A Report to Health Canada:

FETAL ALCOHOL SYNDROME: A HOPEFUL CHALLENGE FOR CHILDREN, FAMILIES AND COMMUNITIES

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"Children born with Fetal Alcohol Syndrome have their own gifts and talents - but not the same as they might have otherwise had in a pregnancy free of alcohol. The family and community are challenged to help children with FAS/E find a place in the community and the world at large."

Marilyn Van Bibber, *It Takes A Community (1997).*

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1 Introduction

1.1 Background to the project

Health Canada, in the Alberta Region, has identified a goal to develop, implement, and evaluate within selected Community Action Program for Children (CAPC) and Canada Prenatal Nutrition Program (CPNP) sites, an Fetal Alcohol Syndrome/Fetal Alcohol Effects pilot project that will enhance and/or introduce secondary and tertiary prevention efforts into existing prevention and early intervention programs. These programs work with pregnant and parenting women and their children to improve the likelihood of positive outcomes in healthy child development and parent/child interactions.

It makes good sense to build on the strengths and capacities of existing programs operating within the province of Alberta. The pilot worked with two selected program sites, Fort McMurray and Lethbridge, with the long term goal of building agency capacity in all CAPC/CPNP programs in Fetal Alcohol Syndrome (FAS) / Fetal Alcohol Effects (FAE) prevention and early intervention. The anticipated long-term outcome of the project is the reduction of significant health effects of FAS/FAE in children and their families.

Equitable Consulting Services was contracted to explore the feasibility of piloting and implementing an Fetal Alcohol Syndrome/Fetal Alcohol Effects project in Alberta. The consultants worked closely with Health Canada, Health Promotion and Program Branch to oversee the development and implementation of the initiative. A multi-disciplinary approach was brought to the project by involving a team of consultants to assist with the initiative (See Appendix A).

The role of the consultant team was to work collaboratively with program stakeholders. They provided a theoretical and conceptual framework, program planning and implementation based on best practices, resource acquisition and adaptation, staff training and evaluation expertise to the selected sites involved with the pilot project.

FAS/FAE is a complex medical and social problem with many gaps in knowledge. For instance, there is no national data on fetal alcohol syndrome or fetal alcohol effects and there are a number of contentious issues, which emerge in the literature. There are no easy or straightforward answers or strategies to address this difficult issue. There is a growing consensus that the best line of defense is prevention and early intervention with women before and during their childbearing years and also targeted at family members, partners and the community (National Council on Welfare, 1997). Several underlying principles guided our approach:

- collaborative in process (consensus building)
- multi-disciplinary in approach
- culturally sensitive
- gender, social and economic determinants analysis
- build on the strengths and capacities of the selected sites
- family centred and community focused
- holistic and innovative

1.2 Terms of Reference

The terms of reference for the project are outlined below.

- Consult on all aspects of the planning, project development, implementation and evaluation phase of the pilot project;
- Work closely with the managers and staff of Health Canada and provide timely information concerning the activities, progress and status of the project (scheduled bi-monthly meetings);
- Present a verbal interim report on the status of the project to Health Canada;
- Consult with site managers, staff, advisory groups involved with the pilot project concerning all aspects of the project. This includes providing information, staff training, resource materials, program models and best practices, community development issues and evaluation;
- Conduct a feasibility study at two Calgary sites;
- Provide a resource file on FAS/FAE; and
- Prepare a final project report including process evaluation and recommendations.

1.3 Advisory Committee

An Advisory Committee was formed to provide an external view to the consultants. Individual members of the Advisory Committee were consulted on a variety of issues. An initial meeting of the Advisory Committee was held January 13, 1998. At that meeting, discussion included the history & context of FAS/FAE Pilot Project, overview of Pilot Project, specifically the goals, and site selection. The BC Model was explained. Evaluation Plans were outlined. An update of the pilot sites was given. An informational handout was distributed. The Advisory Committee validated the approach being taken and provided valuable advice about factors to consider and approaches to this issue. The following members were present at the first meeting:

- Karen Garant-Radke, Health Canada
- Liz McDougall, Health Canada
- Dr. Billie Thurston, University of Calgary, Faculty of Medicine
- Dr. Margaret Clark, Alberta Children's Hospital
- Debbie Kocay, Alberta Alcohol and Drug Abuse Commission
- Anne Stenhouse, Calgary Regional Health Authority
- Catherine Schissel, United Way
- Regina Beckett, Alberta Health
- Brenda Simpson, Consultant, Brenda Simpson & Associates
- Carol Oliver, Consultant, Equitable Consulting Services
- Heather White, Associate, Equitable Consulting Services
- Margaret Edwards, Consultant, Margaret J.A. Edwards & Associates, Inc.

1.4 Site Selection Criteria

Initial dialogue between the consultants and Health Canada led to development of Pilot Site Selection Criteria. These criteria were applied, and the Fort McMurray Children's

Centre and the Lethbridge Native Women's Transition Home were selected. The criteria are listed below:

- Established CAPC program or connection to CPNP funded project
- Culturally sensitive
- Geographical diversity (north, central, south)
- Urban/Rural
- Organizational Stability and Capacity to complete pilot phase
- Community Capacity and Resources
- Identified need and desire to be involved with pilot project and process
- Agrees to work with consultants and take part in formal evaluation
- Ability to travel (minimum 2 meetings)
- Agrees to project management sponsor and budget

The two sites were selected because they met the selection criteria. Both The Children's Centre in Fort McMurray, and the Lethbridge Native Women's Transition Home have established CAPC programs. The Children's Centre in Fort McMurray has a multicultural focus in its urban location and rural outreach preschools in two largely Aboriginal communities. The Lethbridge Native Women's Transition Home and the associated preschool target the Aboriginal community residing in Lethbridge. Both programs had identified FAS/FAE as an issue within the community and a risk factor presented by children participating in their programs.

The two pilot sites were geographically diverse. Fort McMurray in northern Alberta is relatively isolated, over a six hour drive from the nearest large community, and serviced with several daily airline flights. Lethbridge is a much larger urban centre, less than two hours from other large cities. The two sites were also diverse in their organizational capacity. The administrative and organizational structures in The Children's Centre are established and functioning well, while there has been recent administrative reorganization in the Lethbridge Native Women's Transition Home and preschool program.

Both communities have a large variety of professional, health and social services available. Because it is the larger centre, Lethbridge offers more volume and diversity in services. Lethbridge was also identified as having an FAS/FAE steering committee that had been active for over five years, while the Northern Lights Working Committee on FAS/FAE was only initiated in November, 1997. Both sites were interested in involvement with the pilot project and were willing to work within the guidelines of the project.

Candora Society, a CAPC program located in Edmonton sponsored the project and administered the funds. The senior staff of the agency traveled to Vancouver to attend the FAS/FAE conference. As the sponsoring agency, Candora also received a collection of resources and attended the community workshop delivered by the Fort McMurray pilot site.

1.5 Organization of Report

This document is organized around 9 main sections. Section 1 sets the context and framework for the pilot project and the terms of reference for the evaluation component. Section 2 summarizes the medical and sociological literature on FAS/FAE. Section 3 describes effective practices related to prevention and early intervention of FAS/FAE. Section 4 describes the evaluation approach and design. Section 5 provides baseline data and information about the selected pilot sites and Section 6 further describes the activities and learnings from the two pilot sites. Section 7 details the findings of the pilot projects. Section 8 lists the FAS/FAE resources collected and distributed. Finally, section 9 presents the conclusions and the recommendations drawn from the literature review, assessment of best practices, collection of resource materials and the findings of the pilot project.

2 Review of Literature, Resources and Best Practices

To begin the review, the following databases were searched:

- Cumulative Indices of Nursing and Allied Health (CINAHL)
- CCSA-FAS/FAE Information Centre Databases;
- ERIC,
- MEDLINE (Medical Literature); and
- Psych Abstracts.

Resources from these databases were identified, ordered, collected and reviewed. In addition, telephone interviews with FAS/FAE programs across North America elicited additional literature and other media resources developed by specific programs. Attendance at an FAS/FAE conference in Maple Ridge, BC, by two consultants, along with personnel from Health Canada and both pilot sites also lead to the identification of more resources. Two members of the Advisory Committee, Drs. Clarke and Thurston provided additional materials. A selection of resources was compiled for each site and for the Health Canada Library. The following review is based on materials collected from all these sources.

2.1 Fetal Alcohol Syndrome: An Overview

2.1.1 The Science of Fetal Alcohol Syndrome

The adverse effects of maternal alcohol use on the developing fetus have been known since ancient times, however, it was not until 1968, that a formal description appeared in the scientific literature, when Lemoine and colleagues from Nantes, France, reported a set of abnormalities in children born to alcoholic mothers. Lemoine's report went largely unnoticed by the medical community. Streissguth (1997) reports that in the late 1960s, work was underway at the King County Hospital, in Seattle, Washington on infants with "failure to thrive." Dr. Christy Ulleland, through medical records, identified 12 children of alcoholic mothers born within an 8 month period, all of whom had growth deficiencies at birth and later showed developmental delays. In 1973, Dr. David Smith saw one of the children in the Ulleland study and noticed the facial features of the child. He later examined 8 other children in the same study, 4 of whom looked alike and appeared to have the same condition (Streissguth, 1997, p. 38).

The term "***Fetal Alcohol Syndrome***" first appeared in the international medical journal, *Lancet* in 1973. The term was coined by Jones and Smith (1973) to describe a set of features common in children born to mothers who consumed alcohol during pregnancy (Janerich, and Mayne, 1990). This article brought worldwide attention to the condition as a birth defect (Streissguth, 1997, p.39). In 1976, medical texts began to inform readers that alcohol crossed the placenta of a pregnant woman.

Fetal Alcohol Syndrome refers to a constellation of physical abnormalities, most obvious in the features of the face and in the reduced size of the newborn and problems of behaviour and cognition, in children born to women who drank during pregnancy (Stratton et al, 1996). The degree of abnormality in any one measure can vary considerably between individuals and can change over time. The adverse effects of gestational alcohol exposure exist along a continuum with the full expression of FAS at one end of the continuum and more subtle neurobehavioural effects on the other (Loock, 1994). ***Fetal Alcohol Effects*** **and** ***Possible Fetal Alcohol Effects*** describe symptoms on the less severe end of the spectrum.

By 1978, 245 clients with fetal alcohol syndrome had been reported in the medical literature, and FAS was described as the " most frequent known teratogenic cause of mental deficiency in the western world." (Clarren and Smith, 1978 as cited in Streissguth, 1996 p. 9). It was also recognized by this time that prenatal alcohol exposure produces an entire spectrum of effects, of which FAS is the most clearly definable. By the 1980s, the deleterious effects of pre-natal exposure to alcohol were confirmed. The effects were confirmed clinically in the faces of individuals with FAS; empirically through epidemiological studies; and experimentally in the findings of a number of studies in animal labs where both alcohol and other salient factors were under explicit control (Streissguth, 1997, p. 47).

2.1.2 Incidence of FAS/FAE

Literature on the prevalence and epidemiology of FAS is far from consistent or conclusive. Various studies reporting the occurrence of FAS range from 0.5 to 3 births per 1000 in most populations, with some communities having much higher rates (Stratton, et al.,1996, p.6). Hence FAS/FAE may be more common than Down Syndrome (1 in 600) and spinal bifida (1 in 700) combined (Loock, 1994). It is difficult to accurately determine the incidence rate of FAS or FAE , partly because there is no national data available in Canada. The incidence rate in Canada is estimated at between 1 to 3 per 1000 live births (Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women, 1992). This number is likely to be very conservative due to problems of diagnosis and reporting. Incidence rates of FAE are estimated to be 2 to 3 times that for FAS (AADAC, 1996).

There is no national registry for FAS/FAE. The Canadian Perinatal Surveillance System Database has potential for providing some information about diagnosis rates, however, it has just begun collecting data and no statistics are available. The Alberta Health collection of pre-natal alcohol use is also underway, however, it is fraught with methodological concerns about the self-reporting of this information. The dissertation completed by Pace (1997) estimated an incidence rate of FAS among ECS-grade 3 children on the Blood Reserve in southern Alberta to be 5 % (20/400). An additional 120 were identified as requiring further assessment related to FAS. Through out Canada, the extent of the problem of FAS/FAE is underestimated through current population health statistics. The incidence rates appears low due to voluntary reporting systems, inadequate history taking of maternal alcohol use, and the lack of knowledge among health care professionals (Loock, 1990).

The incidence rates of FAS appears to be considerably higher among certain populations, such as Aboriginal Canadians and other socially disadvantaged groups. Studies suggest that the risk of reoccurrence of FAS appears to be substantially higher for families who have one or more children affected by FAS. (771 per 1000 live births). In a study of aboriginal groups in the Yukon and northern British Columbia (Asante and Nelms-Matzke, 1985, as cited in Massey, 1997), the incidence rate was 46 per 100 and 26 per 1000, respectively. In a Vancouver inner city neighborhood where most families consisted of Aboriginal single mothers, a prevalence rate of 50% of live births was not uncommon (Report of the Standing Committee of Health and Welfare, Social Affairs, Seniors and Status of Women, 1992).

The incidence rate of FAE births in Canada is currently unknown although some researchers (Casiro, 1992, as cited in Massey, 1997) have stated that FAE is at least three times as frequent as full-blown FAS. If one follows this to its conclusion, then the communities which had a FAS incidence rate of 46 per 1000 births would also have a FAE incidence rate of 138 per 1000. The inner city neighbourhoods with FAS incidence rates of 50% might therefore have virtually no children born without some degree of Fetal Alcohol Effect. (Massey, 1997 p. 34-35).

2.1.3 The Human and Societal Costs

FAS is expensive and pervasive. It is impossible to measure the exact costs to society of each FAS child. Beyond the health care costs, there are the costs of special education, fostercare, incarceration, financial assistance and social services and the indirect costs related to maladaptive behaviours, goods and services not produced, and most important, the loss of human potential. The estimated lifetime costs related to health and education for one person with FAS may exceed 1.4 million dollars over a lifetime (Streissguth et al, 1996). These costs are staggering considering that FAS is entirely preventable. The costs must be paid by the affected children and families and by the rest of society. For this reason the consequences of alcohol exposure in utero are of concern to us all.

> *My son will forever travel through a moonless night with only the roar of wind for company. Don't talk to him of mountains, of tropical beaches. Don't ask him to swoon at sunrises or marvel at the filter of light through leaves. He's never had time for such things, and he does not believe in them. He may pass by them close enough to touch on either side, but his hands are stretched forward, grasping for balance instead of pleasure. He doesn't wonder where he came from, where he's going. He doesn't ask who he is, or why. Questions are a luxury, the province of those at a distance from the periodic shock of rain. Gravity presses Adam so hard against reality that he doesn't feel the points at which he touches it. A drowning man is not separated from the lust for air by a bridge of thought - - he is one with it -- and my son, conceived and grown in an ethanol bath, lives each day in the act of drowning. For him there is no shore (Dorris, p.264).*

Fetal alcohol syndrome is about more than scientific research, epidemiological studies and incidence data: **at its core FAS is about our children and the immeasurable loss of human potential.**

FAS is also a powerful reminder of children's resilient spirit and their capacity to overcome difficult challenges. Many words have been written about FAS since 1973. Perhaps the most powerful and impactful, remains Michael Dorris's book, ***The Broken Cord*** **(1989)**. His book is a painful and passionately written account of Adam, his adoptive son and their journey to understand and live with FAS. It is a moving account of a child with severe FAS and the devastating impact of alcohol exposure before birth. Dorris' work is particularly important for its' description of the difficulties parents have in managing and accepting their child's limitations and of problems faced by adolescents and adults. Adam's story which later became a television movie awakened the public consciousness about FAS and resulted in an outpouring of U.S. legislation and FAS prevention programs. Adam died in his early 20s, hit by a car that he did not see or hear. Anyone who cares to learn more about this issue should read ***The Broken Cord***.

2.1.4 Fetal Alcohol Syndrome: Guiding Principles

The title of this report, "**FETAL ALCOHOL SYNDROME: A HOPEFUL CHALLENGE FOR CHILDREN, FAMILIES AND COMMUNITIES**" is partially informed and inspired by the voices of parents, caregivers, teachers, doctors, advocates and academics who believe in the ***potential of and the possibilities for*** children and adults affected by alcohol exposure. As we read the literature, traveled to communities and listened to caregivers and health practitioners, a message of hope and resiliency emerged in the discourse. We have tried to communicate and capture this message in this report.

The medical and academic literature tends to paint a bleak picture of the long term outcomes and progress of FAS, supported by grim statistics and studies about secondary disabilities. It is easy to become overwhelmed by the scope and significance of the problem - it is easy to give up on the children and disregard their human potential and contribution. Malbin (1991) is concerned that (the excellent) body of research on FAS generally presents pessimistic outcomes for individuals and the FAS population in general.

The cumulative effect of these pictures of bleak prognoses has implications for the range of services for individuals and families, from clinical practice through prevention efforts. Diane Malbin, an FAS/FAE scholar and activist challenges the dominant perspective: "A very different picture about potential outcomes is now emerging from various points around the country. This portrays positive outcomes for individuals who are FAS/FAE, who are leading rich and fulfilling lives, enjoying loving parenting and relational partnerships, and who are modeling successful intervention in the intergenerational dynamics around alcoholism and substance abuse" (Malbin, 1991).

Diane Malbin, Ph.D. is a cofounder of FAS/Drug Effects Clinical Programs in Portland, Oregon, whose preliminary findings on positive outcomes for people with FAS/FAE and their families have been presented in the U.S. and Canada. She is an educator, activist, and a mother of a child with FAE.

Working in the area of FAS/FAE can elicit a range of emotional and intellectual responses - effective practices and community-based interventions need to be directed by guiding principles and positive perspectives. Practitioners and activists from across Canada spoke of the importance of working from a place of hope, compassion and respect for the children and families affected by FAS/FAE.

"Instead of getting angry at mothers who produce children with FAS/FAE, citizens should invest their time and effort to ensure that the situation never has the opportunity to repeat itself or recycle itself in future generations." Dr. Ann Streissguth. ***FAS: A Guide for Families and Communities (1997, p.274).***

Dr. Christine Loock, a pediatrician and medical consultant with the British Columbia Ministry of Children and Families stated in conversation: "When I diagnose and care for a child with FAS, I really have three patients: the child that I am currently caring for, the child that came before and the child yet to be born." She works from a very integrated and holistic prevention approach. Dr. Loock understands from years of working with high-risk women, that a harm reduction approach is really about showing compassion for birth mothers and believing in their potential for change. She recognizes that supporting birth mothers and "mothering the mother" is pivotal in preventing FAS in future children and increasing protective factors for children currently under their care.

To effectively help children made vulnerable by prenatal exposure to alcohol, it is essential to work from a place of ***hope and compassion*** - a hopeful attitude will positively reinforce a child's perception of herself and will sustain parents and other adults through difficult times. It is not helpful to work from a place of fear and emotionality. It is too easy to blame and isolate birth mothers, systematically marginalizing them in the discourse and service delivery systems. Often children are removed from the care of natural parents and some children need the protection of the state intervention. However, the tendency to remove children can result in a lose-lose-lose dynamic. Children then suffer the loss of parental connection, can go undiagnosed as FAS and remain at risk; high-risk mothers are not treated or intervened with and subsequent alcohol-related births are not prevented; and professionals miss the opportunity to effectively intervene with the family system.

Malbin believes that the common stereotype of the population at risk for giving birth to FAS/FAE children is aboriginal, black, poor, uneducated, inner-city and low-income. This stereotype is dangerous. It exists in part to meet the need of the dominant culture... uncomfortable professionals and the general population... to have a focus for the problem, an identifiable group on whom to focus the considerable anger, frustration and moral indignation generated by this issue. At risk families are rarely seen as professional, white, middle-class... our friends, sisters, mothers or grandmothers (Malbin, 1993, as cited in Kleinfeld and Wescott, 1993).

Marilyn Van Bibber, an Aboriginal woman and FAS consultant from British Columbia, writes eloquently about traditional and fundamental teachings of indigenous peoples. The underlying principle of ***humility*** needs to be heeded when responding to the complexities of FAS. The complexity and emotionality attached to the problem of FAS can lead to simplistic analysis and solutions. She cautions against quick actions that do not guarantee good results. Community action and development is a learning process that cannot be forced or rushed - it is a process that must be guided by respect, caring and being supportive. It is fundamentally important to begin "where communities are at." Every community will have strengths and capacities and specific needs and barriers to address.

Respect is a fundamental teaching of indigenous peoples. When working with Aboriginal people and their communities it is very important to respect and understand the traditional First Nations and Inuit teachings. Understanding the root causes of FAS, both sociological and economic, are key to developing effective practices within the Aboriginal communities. Van Bibber writes, " The deterioration of Aboriginal political and social institutions; the suppression of traditional spirituality, culture, and language; the apprehension of Aboriginal children and loss of traditional lands and economies is the legacy of Aboriginal peoples after European contact in the new world. The current health and socio-economic conditions trace their beginnings to these historic events. Many aboriginal communities are working actively attempting to counter the impact of colonialism" (Van Bibber, 1997, p.13).

It Takes a Community (1997)
*All living creatures respond to the positive energy of kindness...**caring** is something that can be done in the prevention (and intervention) of FAS/FAE. It costs nothing and takes no formal training... just practice.*
Van Bibber,

It is the re-building and re-visioning of Aboriginal cultures and institutions underway today that provide a foundation and give direction to successful FAS/FAE strategies. Approaches need to consider the root causes of alcohol abuse and acknowledge the current level of community awareness and development around the issues of FAS/FAE. Communities must find their own path towards healing and helping those affected by prenatal alcohol exposure. Effective strategies for FAS/FAE prevention and intervention must reflect the history of the community and its current needs and capacities. Embedding FAS/FAE initiatives into existing community development processes, such as education, recreational, programs for women and health care initiatives are documented as strategically effective (Van Bibber, 1997, p. 14).

And finally, it is overwhelmingly clear from the literature that FAS is multifactorial requiring the ***cooperation and participation*** of multiple disciplines and sectors. FAS is not the exclusive purview of one discipline or one sector - the problem belongs to all of us.

2.1.5 Fetal Alcohol Syndrome: Diagnostic Criteria

2.1.5.1 Primary Characteristics

Fetal Alcohol Syndrome is diagnosed when three primary characteristics occur together:

1) growth deficiency for height and weight below the 10th percentile when corrected for gestational age. Although growth retardation is characteristic of exposure to many drugs, it is a defining characteristic of FAS and other alcohol-related birth defects.

2) congenital abnormalities, or dysmorphic features, occur as a result of exposure to alcohol during the embryonic or early fetal period of development. The abnormalities, primarily observable in the face, include short palpebral fissures, a pattern of flattened

midface, smooth and/or long philtrum, and thin upper lip. Ears may be low set and rotated, and this may be associated with abnormalities of the inner ear.

3) and some manifestations of Central Nervous System dysfunction as manifested by microcephaly (head circumference below the 3rd percentile) developmental motor problems, neurologic signs, and/or seizures delay, hyperactivity, attention and/or memory deficits, learning disabilities, intellectual deficits (Streissguth et al, 1996, p.11).

2.1.5.2 Secondary Characteristics of Fetal Alcohol Syndrome

The possible effects of fetal exposure to alcohol are not limited to just three areas. Children with FAS are also at higher risk for eye problems, malformations of the head, ears nose, mouth, palate and jaws, dental abnormalities, abnormal development of the heart, liver, and kidneys, urogenital defects, respiratory defects, and problems with the immune system (Abel, 1984 as cited in Massey, 1996). Clinical studies also indicated limb and joint abnormalities including skeletal anomalies, club foot, hip dislocation, fused ribs, spinal bifida and scoliosis are common in FAS or FAE (Massey, 1996).

2.1.5.3 Fetal Alcohol Effects

If symptoms are present in fewer than all three diagnostic criteria, then a diagnosis of *Fetal Alcohol Effects (FAE)* is usually made. Some researchers, however, argue that the distinction between FAS and FAE is an artificial one. Alcohol-related birth defects, including FAS occur along a continuum of severity, with miscarriage and stillbirth being the most drastic outcomes at one end, and various birth defects not sufficient to be classed as FAS at the other end of a continuum of damage (AADAC, 1996).

The affected individual might demonstrate signs in two of the three defining categories or have some other deficit that is probably the result of their prenatal exposure (Coles et al, date n.k.). Such a child may not be growth retarded but shows some dysmorphia and evidence of mild neurological problems. According to Streissguth and Randels (1989), the class of these children is probably larger, but less easy to identify, than those with FAS. Although they are less frankly affected, such children were found to be experiencing equally poor academic outcomes, and to show social/behavioural problems than, children with the full syndrome.

Most children with FAE are not identified as alcohol-affected. Other diagnostic labels are applied such as attention deficit disorder, attachment disorder, learning disabled, oppositional defiant disorder. Failure to accurately identify the organic brain damage that is part of FAS/FAE may exacerbate the problems and lead to frustration, anger and place the child at further risk.

Massey (1996) reports that the diagnostic criteria first established in 1980 has since been revised and extended under the auspices of the National Academy of Sciences (1966). "While the original term of Fetal Alcohol Syndrome still stands, it has now been expanded to include other diagnostic markers. Clinicians can now distinguish between Fetal Alcohol

Syndrome with Confirmed Maternal Alcohol Exposure, Fetal Alcohol Syndrome without Confirmed Maternal Alcohol Exposure, and Partial Fetal Alcohol Syndrome with Confirmed Maternal Exposure." (Massey, 1996, p.34).

Diagnosing FAS/FAE and other alcohol-related birth defects is medically complex. Clinicians have for years, struggled with diagnostic terminology and it is evident from the literature that diagnostic criteria will continue to evolve as further research is completed. The following Table 1 presents the latest diagnostic categories as defined by the Committee to Study Fetal Alcohol Syndrome, under the auspices of the Institute of Medicine of the National Academy of Sciences (Stratton et al, 1996, p. 4-5).

TABLE 1 Diagnostic Criteria for Fetal Alcohol Syndrome (FAS) and Alcohol-Related Effects.

Fetal Alcohol Syndrome

1. FAS with confirmed maternal alcohol exposure[a]

A. Confirmed maternal alcohol exposure[a]

B. Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the premaxillary zone (e.g., flat upper lip, flattened philtrum, and flat midface)

C. Evidence of growth retardation, as in at least one of the following:
- low birth weight for gestational age
- decelerating weight over time not due to nutrition
- disproportional low weight to height

D. Evidence of CNS neurodevelopmental abnormalities, as in at least one of the following:
- decreased cranial size at birth
- structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
- neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

2. FAS without confirmed maternal alcohol exposure

B, C and D above.

3. Partial FAS with confirmed maternal alcohol exposure

A. Confirmed maternal alcohol exposure[a]

B. Evidence of some components of the pattern of characteristic facial anomalies

Either C or D or E

C. Evidence of growth retardation, as in at least one of the following:
- low birth weight for gestational age
- decelerating weight over time not due to nutrition
- disproportional low weight to height

D. Evidence of CNS neurodevelopmental abnormalities, as in:
- decreased cranial size at birth
- structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
- neurological hard or soft signs (as age appropriate) such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

E. Evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulsive control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention, or judgement

Alcohol-Related Effects

Clinical conditions in which there is a history of maternal alcohol exposure,[a,b] and where clinical or animal research has linked maternal alcohol ingestion to an observed outcome. There are two categories, which may co-occur. If both diagnoses are present, then both diagnoses should be rendered:

TABLE 1 Continued

Alcohol-Related Effects (continued)

4. Alcohol-related birth defects (ARBD)

List of congenital anomalies, including malformations and dysplasias

Cardiac	Atrial septal defects	Aberrant great vessels
	Ventricular septal defects	Tetralogy of Fallot
Skeletal	Hypoplastic nails	Clinodactyly
	Shortened fifth digits	Pectus excavatum and carinatum
	Radioulnar synostosis	Klippel-Feil syndrome
	Flexion contractures	Hemivertebrae
	Camptodactyly	Scoliosis
Renal	Aplastic, dysplastic	Ureteral duplications
	Hypoplastic kidneys	Hydronephrosis
	Horseshoe kidneys	
Ocular	Strabismus	Refractive problems secondary to small globes
	Retinal vascular anomalies	
Auditory	Conductive hearing loss	Neurosensory hearing loss
Other	Virtually every malformation has been described in some patient with FAS. The etiologic specificity of most of these anomalies to alcohol teratogenesis remains uncertain.	

5. Alcohol-related neurodevelopmental disorder (ARND)

Presence of:

A. Evidence of CNS neurodevelopmental abnormalities, as in any one of the following:
  - decreased cranial size at birth
  - structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
  - neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

and/or:

B. Evidence of a complex of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulsive control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention, or judgement

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[a] A pattern of excessive intake characterized by substantial, regular intake or heavy episodic drinking. Evidence of this pattern may include frequent episodes of intoxication, development of tolerance or withdrawal, social problems related to drinking, legal problems related to drinking, engaging in physically hazardous behavior while drinking, or alcohol-related medical problems such as hepatic disease.

[b] As further research is completed and as, or if, lower quantities or variable patterns of alcohol use are associated with ARBD or ARND, these patterns of alcohol use should be incorporated into the diagnostic criteria.

2.1.6 The Diagnostic Process

Two critical pieces of documentation are required to reach a confirmation that an individual has been affected by fetal alcohol exposure: 1) an examination of the individual and, 2) historical information relative to prenatal alcohol exposure. The alcohol/drug use history of the biological mother is often the most difficult to obtain and some medical practitioners are reluctant to diagnose without confirmation of maternal alcohol consumption. When a diagnosis is made later in life, it is often an adoptive parent, a social worker or even the adult with FAS that provides information. Often, there can be no confirmation of maternal alcohol abuse or use.

> *"The FAS diagnosis is made only by clinical examination; at this time, there are no confirming laboratory tests and no validated checklists. Thus, the diagnosis is dependent on the clinical expertise of the diagnostician. Traditionally, dysmorphologists or clinical geneticists are most skilled at detecting birth defects" (Streissguth, 1997, p.22).*

The literature suggests that diagnosis of FAS is often difficult for several reasons.

FAS can be diagnosed at birth but it is often overlooked in newborns. In infancy, central nervous system impairments and facial abnormalities due to FAS may be difficult to identify. FAS is not diagnosed by the presence or absence of any single major malformation that would be recognizable at birth. Streissguth states that "seeing is not recognizing" (Streissguth, 1997, p.22). The clues to recognition lie in a subtle interplay of physical and psychosocial characteristics, maternal alcohol history, and the children's own behavioural history. The initial recognition of FAS for an individual clinician often involves the "A ha" phenomenon.

While the "classic" facial features of FAS are distinct and can be readily distinguished from other disorders, even an expert may have difficulty confirming the diagnosis of FAS when the phenotype is "incomplete" or "atypical" (Stratton et al, 1996). Disorders that are confused with FAS because of somewhat similar appearance are Aarskog syndrome, Williams syndrome, Nooanan's syndrome, Dubowitz syndrome, Bloom syndrome, fetal hydantoin syndrome, maternal PKU fetal effects, and fetal toluene syndrome, Fragile X syndrome, velocardiofacial syndrome, Turner's syndrome, and Opitz syndrome (Stratton et al, p.79). Research indicates that FAS and other alcohol-related birth defects will continue to present many diagnostic difficulties and challenges. Experts suggest that a trained clinician can make the diagnosis for purposed of screening and referral but that a medical diagnosis of FAS remains the purview of dysmorphologists and clinical geneticists (Stratton et al, 1996).

Some professionals question the usefulness of the diagnosis and fear "labeling" or worse mis-diagnosing children. If an FAS child avoids being labeled as such, it is highly likely he/she will receive another label: such as "stupid", "lazy", "stubborn", "conduct disordered" or "crazy". Experts believe that an accurate diagnosis for a neurologically-based disorder is a strong protective factor, a starting place from which to formulate a life plan. In the words Mary Vandenbrink, an adoptive mother of two children with FAS, a proper diagnosis "is much kinder and removes the blame from the child".

Obtaining an accurate diagnosis is further complicated and hindered by maternal denial which often accompanies alcohol abuse. Furthermore, the absence of maternal confirmation on medical records should not be interpreted as "no prenatal exposure"

Diagnosis involves an interdisciplinary work-up including assessment of vision and hearing, dental problems, language, motor coordination, growth and development patterns, craniofacial features, as well as a psychological assessment. It should also involve assessment of the child's strengths, special interests and abilities. The diagnosis needs to be made by an expert in birth disorders or a pediatrician with extensive experience in the field; and there are not enough expert diagnosticians or clinics that specialize in FAS diagnosis.

> *"Since his birth, I have been engaged, with my son, in a fight for his life.*
> *Before my adopted son was born, I considered whether I would keep him if he were damaged by his birth mother's alcoholism. After his birth, I saw his first smile and dreamed that one day he would be distinguished among men for the warmth and integrity of his character.*
> *Would I keep him if he were damaged? It seemed a faded question months later when the doctors first discussed the possibility of fetal alcohol syndrome."*
> *Sally Caldwell, mother of Antone in* ***Fantastic Antone Succeeds (1993).***

Despite of the inherent difficulties associated with a medical diagnosis the research is clear: an accurate and early diagnosis (before the age of 6) is often a protective factor that improves the likelihood of long-term positive outcomes for alcohol-affected children and their families. (Streissguth, 1996).

A medical diagnosis serves several purposes: to facilitate communication among clinicians; to facilitate communication between clinician and patient and parents; to assist in the study of pathophysiology and etiology; and to guide treatment. "Placing a patient in a diagnostic category confers both benefits and disabilities. For example, the diagnosis of FAS may validate a patient's disability and facilitate appropriate interventions and social benefits. On the other hand, the diagnosis may also be used to stigmatize and to create self-fulfilling prophecies about the future that could be detrimental to the patient and his or her family." (Stratton et al, p, 2).

2.1.7 Alcohol as a Teratogen: What does the research show?

It is now widely accepted that alcohol is a potent *neurobehavioural teratogen* associated with a wide range of adverse effects on the human fetus and the offspring of women who drink during pregnancy. There are four main things that can happen to a developing fetus that is exposed to a teratogen: death, malformations, growth deficiency and functional deficits: alcohol causes all four outcomes (Streissguth, 1997, p. 56). Alcohol is one of a number of chemical compounds known to be toxic to the developing central nervous systems of human. Of all the substances of abuse, including heroin, cocaine, tobacco and marijuana, alcohol has by far the most serious neurobehavioural effects on the fetus (Stratton et al, p. 35).

A number of key learnings can be drawn from two decades of research on teratogenic effects of alcohol as reported by Streissguth in her book, ***Fetal Alcohol Syndrome, A Guide for Families and Communities (1997).***

Dr. Ann Streissguth is Director of the Fetal Alcohol and Drug Unit and Professor in the Department of Psychiatry in Behavioural Sciences at the University of Washington School of Medicine in Seattle. Her 25 years of work with families and communities and her academic research distinguished her as a pioneer in the study of FAS. Perhaps more than any other scholar she writes with compassion, wisdom and authority on the essential issues surrounding the complexities of prenatal exposure to alcohol.

Fetal alcohol syndrome is an organic brain disorder caused by prenatal alcohol exposure. FAS is a birth defect that manifests itself in the areas of reasoning, memory and judgment. When a pregnant woman drinks alcohol, it crosses the barrier of the placenta. The brain and central nervous system of the unborn child are especially sensitive to disruption by the effects of prenatal alcohol exposure.

Alcohol is a potent teratogen. All pregnant women and those planning a pregnancy are advised to abstain from alcohol. Alcoholic women who are able to stop drinking during a pregnancy, particularly early in pregnancy, are less likely to have children with FAS/FAE and to have improved pregnancy outcomes. The warnings from public health officials such as the Surgeon General in the U.S. and Health Canada should be strictly adhered to.

Dose, timing, and pattern of exposure modify the prenatal effects of alcohol. The harmful effects of alcohol are not limited to heavy chronic exposure. Moderate, sporadic, bingeing alcohol consumption can cause negative outcomes at any time during gestation.

Individual differences in the mother and the child modify the effects of prenatal exposure, in terms of both the severity and the type of central nervous system effects. Chronicity or stage of alcoholism and birth order may be relevant. Research indicates that children with FAS are often produced at or near the end of an alcoholic mother's reproductive history and that once an alcoholic mother has produced a child with FAS, she is likely to continue having children with FAS. The youngest children in a family are often the most severely affected. The best estimate from existing data is that between 25% and 45% of women with chronic alcoholism will give birth to children with FAS if they drink heavily during pregnancy (Streissguth, 1997, p. 80).

There is now evidence that alcohol damages the female reproductive system. A broad range of disorders can occur including, amenorrhea, anovulation, lateral phase dysfunction, and ovarian pathology. The consequences can range from infertility, to spontaneous abortion and impaired fetal growth development (Mello, Mendelson, and Teoh, 1989, cited in Streissguth, 1997).

Organic brain damage can occur without the accompanying facial characteristics or physical manifestations from lower doses and frequency of exposure to alcohol. Children with FAE and Alcohol Related Neurological Damage can also have brain damage.

Many of the behaviours that people with FAS/FAE display and engage in, are the result of disrupted brain development and brain damage. Prenatal exposure can cause hyperactivity, distractibility, poor personal boundaries, inability to manage anger, perceptual disorders, poor impulse control, difficulty learning from experience, and perserative problem-solving approaches.

The effects of prenatal exposure last over the lifespan; FAS/FAE does not go away; nor is it curable. FAS and other alcohol-related birth defects are completely preventable. FAS is arguably the most common known nongenetic cause of mental retardation. FAS constitutes a major public health concern. (Stratton et al, 1996, p. 7)

2.1.7.1 A Multifactorial Model

The following model (Stratton et al, 1996, p. 47) attempts to illustrate the " point that the expression of adverse alcohol effects in the offspring from birth to adulthood can be influenced by factors that include the critical period during pregnancy when exposure occurs, the pattern and amount of maternal alcohol intake, and a host of other biological and environmental variables that can possibly impact both the pre- and the postnatal periods."

A MULTIFACTORIAL MODEL

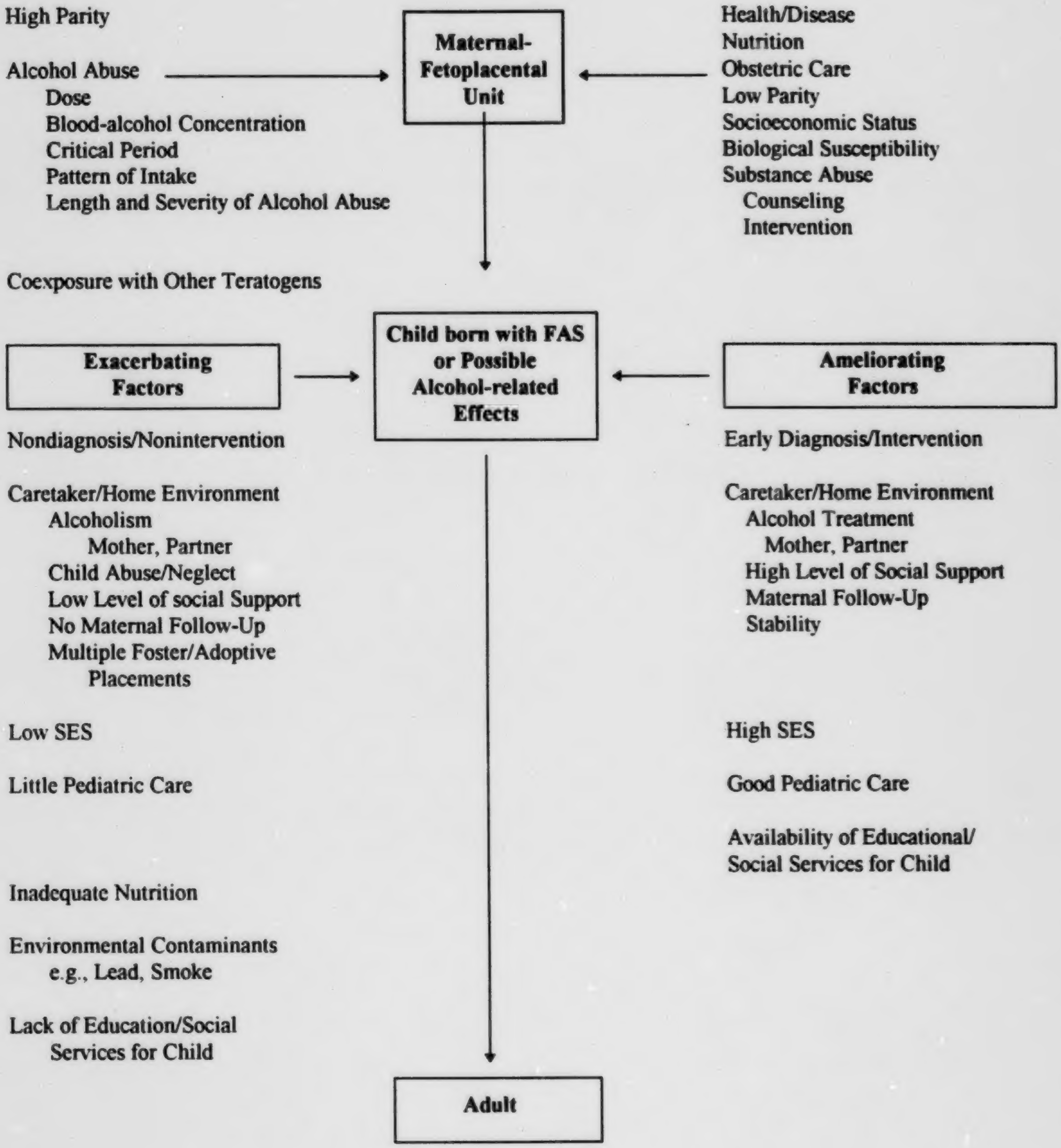

High Parity
Alcohol Abuse
Dose
Blood-alcohol Concentration
Critical Period
Pattern of Intake
Length and Severity of Alcohol Abuse
Coexposure with Other Teratogens
Maternal-Fetoplacental Unit
Health/Disease
Nutrition
Obstetric Care
Low Parity
Socioeconomic Status
Biological Susceptibility
Substance Abuse
Counseling
Intervention
Exacerbating Factors
Child born with FAS or Possible Alcohol-related Effects
Ameliorating Factors
Nondiagnosis/Nonintervention
Caretaker/Home Environment
Alcoholism
Mother, Partner
Child Abuse/Neglect
Low Level of social Support
No Maternal Follow-Up
Multiple Foster/Adoptive Placements
Low SES
Little Pediatric Care
Inadequate Nutrition
Environmental Contaminants
e.g., Lead, Smoke
Lack of Education/Social Services for Child
Early Diagnosis/Intervention
Caretaker/Home Environment
Alcohol Treatment
Mother, Partner
High Level of Social Support
Maternal Follow-Up
Stability
High SES
Good Pediatric Care
Availability of Educational/ Social Services for Child
Adult

TABLE 2. Theoretical influences on the expression of prenatal alcohol exposure.

2.1.8 Separating Myth from Reality

Streissguth (1997, p. 121-123) identifies seven common misconceptions about FAS/FAE that can hinder true understanding of the complexities of the lives of people with the disorder.

1. Myth: *People with FAS/FAE always have mental retardation.*
   - Some people with FAS are mentally challenged, others are not.
   - People with FAS can have normal intelligence
   - FAS is brain damage and those affected have specific areas of strength and weaknesses

2. Myth: *The behaviour problems associated with FAS/FAE are the result of poor parenting or a bad environment.*
   - Brain damage can lead to behaviours problems because brain damaged people don't process information the same way that other people do, and they don't always behave the way they are taught or expected to.
   - FAS children present many challenges to parents throughout the lifespan.
   - Parents need information, support, help and respite, not criticism.

3. Myth: *Admitting that children with FAS/FAE have brain damage means that society has given up on them.*
   - Society does not give up with other children with birth defects.

4. Myth: C*hildren eventually outgrow FAS/FAE.*
   - FAS lasts a lifetime, but the manifestations and type of problems change with each developmental stage of life.

5. Myth: *Diagnosing children with FAS/FAE will thwart their development.*
   - A diagnosis names the problem, helps parents to set realistic goals for their children.

6. Myth: *It is* useless *to diagnose FAS/FAE because there is no "real" treatment approach.*
   - A diagnosis allows for a treatment plan and a partnership between health care providers, educators, parents and the affected child.

7. Myth: *People with FAS/FAE are unmotivated and uncaring, always missing appointments or acting in ways that society considers irresponsible or inappropriate.*
   - The behaviours result from organic brain damage and often the explanation lies in poor judgement, inability to solve problems, memory problems, or simply being overwhelmed.

2.1.9 A Lifespan Approach to Understanding FAS

FAS/FAE have been recognized for the past 25 as a major known cause of developmental delay and disability. Yet, it is only in the past 10 years that the lifelong implications of these disabilities have slowly begun to be recognized. Understanding the life problems that characterize people with FAS/FAE as they grow and mature is essential to developing effective interventions, estimating costs to society, and mandating appropriate public policies.

> *My daughter would say to you: I am not a statistic. I am not like you, but my brain works. I am not an FAS case, I am a person with FAS. I have a disability, but my spirit is whole. (Jan Lutke, 1996).*

A lifespan approach is not concerned with benchmarks or traditional markers of success, rather it embraces a holistic concept of health and well-being and the basic humanity of each individual. Only when communities adopt a life-span approach to understanding and preventing alcohol-related birth defects, extending help to both alcohol-abusing mothers and their children and then to the children as they become parents, can the condition really be ameliorated.

Dr. Robin LaDue (1989) from the Fetal Alcohol and Drug Unit, University of Washington School of Medicine prepared a psychosocial needs profile associated with FAS/FAE over the lifespan. Table 3 is a summary adaptation of LaDue's profile.

Table 3: Psychosocial Needs Associated with FAS/FAE

Age	Problems and Concerns	Recommendations
Infancy and Early Childhood Ages birth 5 years	▪ Poor habituation ▪ Sleeping disturbances; poor sleep/wake cycle ▪ Poor sucking responses ▪ Failure to thrive ▪ Delays in walking and talking ▪ Delayed toilet training ▪ Difficulty following instructions ▪ Temper tantrums and disobedience ▪ Distractibility	▪ Early identification and diagnosis ▪ Intervention with the birth mother/ and or foster parent ▪ Education of parents regarding physical and psychosocial needs of an infant or child with FAS/FAE ▪ Careful monitoring of physical development of children ▪ Safe, stable and structured home ▪ Assignment of case manager for coordination of services and support to parents ▪ Placement of a child in a preschool ▪ Respite care for caretakers
Latency Period Ages 6-11 years Latency Period	▪ Easily influenced and difficulty predicting and/or understanding consequences ▪ Gives an appearance of capability without actual	▪ Safe, stable and structured home or residential placement ▪ Careful and continued monitoring of health issues and existing problems

Age	Problems and Concerns	Recommendations
Ages 6-11 years (cont'd)	abilities ▪ Difficulty separating facts from fantasy ▪ Temper tantrums, lying, stealing, disobedience and defiance of authority ▪ Delayed physical and cognitive development ▪ Poor comprehension of social rules and expectations	▪ Appropriate educational and daily living skills placement ▪ Help caretakers establish realistic expectations and goals ▪ Caretakers support group ▪ Psychological, educational and adaptive evaluations on a regular basis ▪ Use of clear, concrete and immediate consequences for behaviour ▪ Respite care for caregivers ▪ Case manager role expands to include liaison between parents, schools, health care providers and social service agents
Adolescence Ages 12-17 years	▪ Lying, stealing and passivity in responding to requests ▪ Faulty logic ▪ Egocentric; has difficulty comprehending and/or responding appropriately to other people's feelings, needs and desires ▪ Low motivation ▪ Low self-esteem ▪ Academic ceiling which is usually around grade 4 for reading and grade 3 for spelling and arithmetic ▪ Depression ▪ Pregnancy and/or fathering a child/ren ▪ Loss of residential placement	▪ Education of caretakers and persons regarding sexual development and healthy sexuality, birth control options and protection from sexually transmitted diseases ▪ Planning and implementation of adult residential and vocation training and placement ▪ Appropriate mental health interventions as needed ▪ Respite care for caretakers ▪ Caretakers support group ▪ Safe, stable and structured home or other residential placement ▪ Shifting of focus from academic skills to daily living and vocational skills ▪ Careful monitoring of social activities and structuring of leisure time ▪ Working towards increased independence by teaching to make healthy choices
Adulthood Ages 18+ years Adulthood	▪ Residential placement ▪ Economic support and protection ▪ Job training and placement	▪ Guardianship for funds ▪ Specialized residential and/or subsidized housing ▪ Specialized vocational training

Age	Problems and Concerns	Recommendations
Ages 18+ years (cont'd)	▪ Depression and suicidal ideation ▪ Pregnancy or fathering of a child ▪ Social and sexual exploitation, or inappropriate behaviours ▪ Increased expectations of the person by other people ▪ Increased dissatisfaction towards person by other people ▪ Withdrawal and isolation ▪ Unpredictable behaviour ▪ Involvement with the criminal justice system	and job placement ▪ Medical and health care support and subsidization ▪ Acknowledgment of the person's skills and limitations ▪ Personal advocates to ensure the above occurs

> *Abandoned by his alcoholic mother at birth, Kenny was the first newborn baby in the world diagnosed with FAS (Jones and Smith, 1973). I used to go down to the newborn nursery to play with him and study his behaviour. I noticed that the nurses, although they liked him a lot, complained about how much time it took to feed him. Whenever I stopped by, someone had him in the rocking chair, trying to get him to finish his bottle. I also noticed that when I stimulated him from a light sleep - - with a gentle shake of a rattle or a bell repeated at brief intervals - - he got increasingly aroused and excited, waking up jittery and hyperaroused. He just couldn't seem to habituate. (Streissguth, 1997 p. 129).*

> *Structure rather than control made the difference between peace and war in their home... identification is pivotal. It is hard to think of a more radical perceptual shift than the one between "willful misconduct" to " organicity", from "bad child" to "handicapped child with potential."*
> *Diane Malbin, speaking of her daughter Devorah*

2.2 Secondary Disabilities Associated with FAS/FAE

Secondary disabilities are those disabilities that a person is not born with, and that could presumably be ameliorated through better understanding and appropriate interventions. Most secondary disabilities in people with FAS/E begin to develop in early adolescence.

In their landmark study on Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects, Streissguth, Barr, Kogan and Bookstein (1996) document the following as potential secondary disabilities related to FAS/FAE:

- early school drop-out
- alcohol and drug abuse problems
- having children they can't care for
- joblessness
- homelessness
- trouble with the law
- mental health problems (anxiety, depression, sleep disorders)
- inappropriate sexual behaviour
- premature death

It is critical to recognize and understand that secondary disability research is based primarily on examination of older children and adults who have not had an early diagnosis or may have lived with a misdiagnosis for many years. The implications of late diagnosis on the development of secondary disabilities are staggering. Lifelong costs, primarily related to secondary disabilities, of a person with FAS/E have been estimated to range from 1 to 1.4 million dollars.

It is also important to note that people with FAE are at greater risk of secondary disabilities due to lack of proper and early identification of their FAS/FAE. The Secondary Disabilities Project by the University of Washington, (Streissguth et al, 1996) studied the frequencies of problems which occur in the FAS/FAE population in the absence of intervention.

The study included 426 people with FAS and FAE and found the following:

Number	426	
Ages	12-49 years	
Male	58%	
Female	42%	
Caucasian	66%	
Native American	27%	
African American	5%	
Other	2%	
Diagnosis	FAS	FAE
	30%	70%

Disabilities:	**FAS**	**FAE**
Substance Abuse	21%	32%
Mental Illness	32%	49%
School Problems	40%	63%
Trouble with the Law	51%	68%
Homelessness	16%	30%
Violent or Threatening Behaviour	35%	50%
One or More Secondary Disability	74%	93%

Early FAS/FAE diagnosis is recognized throughout the research findings as a strong "universal" protective factor for all secondary disabilities. An early diagnosis may help the family better understand the root of their child's developmental delays and behavioural problems and empower them to advocate for appropriate services and early intervention.

A number of other factors beyond early diagnosis may ameliorate the development of secondary disabilities. These are summarized in the Streissguth et al, 1996 study as the following:

- **Provision of stable long-lasting placements in nurturant homes of "good quality".** Many alcohol-affected individuals come from dysfunctional, transient, and abusive living situations. More effective community and family support services are essential to avoid the development of secondary disabilities.

- **Improving the circumstances of children in alcohol/drug abusing homes.** Streissguth's research indicates that children in this type of environment are at greater risk for developing alcohol and drug abuse problems, facing confinement, missing or dropping out of school, experiencing trouble with the law and developing inappropriate sexual behaviours.

- **Intervening to prevent violence and sexual abuse against people with FAS/FAE.** Violence against the person affected by FAS/FAE was almost a universal risk factor for all secondary disabilities in the Streissguth study.

- **Development, evaluation and implementation of additional methods to detect people with FAS/FAE who may have been misdiagnosed.**

- **Cooperation among communities, families and people with FAS/FAE in working together to develop solutions that are beneficial to all.** Not all wisdom comes from academic research and study. A great deal of information and best practices can be gathered and shared at the informal level within and between families, communities, teachers, therapists and service providers. The common vision of the best possible future for the alcohol affected individual must be the guiding point for this work.

The reality with alcohol affected children is that we do not know the limits of what can be accomplished. Secondary disabilities are, quite often, the worst case scenario resulting primarily when a child goes undiagnosed or is misdiagnosed. Overwhelmingly, research and advocates are telling us that possibilities and brighter futures for FAS/FAE children exist when we know what we are dealing with, when we start early, and when we create home and community environments adapted to their unique needs. (Kleinfeld and Wescott, 1993)

2.3 Preventing Secondary Disabilities

2.3.1 The Importance of an Accurate Diagnosis and Early Intervention

"The impact of prenatal exposure to alcohol is long-lasting, raising challenges at each stage of development, and continuing through puberty. In the most heart-breaking situations, alcohol-affected children are raised with no awareness of their disabling brain damage. Parents and other caregivers may see these children's disobedience as willful; professionals can view the distraught parents as inept. But we do not yet know the best possible outcomes possible for fetal alcohol-affected children. Some may do well. Family experiences and expectations, cultural practices, schooling, and peer contact are all important; a good environment can buffer alcohol effects. ***We believe that informed early intervention can bring hope to all parents and children dealing with prenatal alcohol exposure." (Streissguth et al, date unknown)***

Like children with other disabilities, those with FAS and FAE benefit from early diagnosis and intervention. Early intervention may be one of the most critical services that early childhood educators can provide for children. Early diagnosis/assessment of FAS/FAE leads to early intervention, and a better outcome. Children who show early developmental delay can benefit from services such as speech/language therapy, occupational therapy, special needs pre-schools, and early learning assistance. Remedial and preventative services can improve long-term outcomes if the programs are sustained. FAS is a life-time disability; children do not "simply outgrow it" and there needs to be sustained support.

Stratton suggest the early identification of a child with FAS can be used as a marker that will lead to intervention with the mother for her own treatment and for the prevention of births of subsequent children with FAS. "This is the best chance to prevent alcohol-related trauma and disease in the mother, increase the chance that she will be able to mother her child, decrease foster placement, and prevent the birth of more children with FAS." (Stratton et al, 1997, p.79).

FAS/FAE are often referred to as the "hidden disability" because the affected child usually does not have a visible handicap. Because of the nature of the social skills deficits and the behavioural problems associated with FAS, the affected child can present as a real challenge and test the patience of family, teachers and peers. Social isolation, criticism, failure at school leads to a progressive damaging of self-worth. The importance of building self-esteem in these children cannot be overstated (British Columbia FAS Community Action Guide, 1997).

> *At the time the child is diagnosed, the family is often at a pivotal point in their lives. Diagnosis is usually greeted with relief (I'm not a bad parent, "" I knew something was wrong), followed by depression, desperation, and finally, determination. Parents must be given back the power that time has taken from them, the years spent trying to slay the wrong dragon. They must address their own issues, vent anger, grieve losses, and move onto the acceptance of the reality of FAS/FAE. This change will best occur in the company of other parents in a support group. This time of healing is also a time for self-assessment, reflection and education." (Fantastic Antone Succeeds, 1993,p.74)*

Early diagnosis and intervention are critical processes so that the parents, caregivers and the child can distinguish between the child and the behaviours. They can understand that the behaviour is not willful misbehaviour but a result of a neurological disorder. When the parents understand the neurological basis for difficulties and the child understands (with simple explanations of the diagnosis) it is not his or her fault, they have taken an important first step in developing a life-plan that can accommodate and circumvent the problems.

2.3.2 Suggested Interventions

The British Columbia FAS Community Action Guide (1997) provides an overview of appropriate interventions that work with infants and young children:

2.3.2.1 Interventions for young children and families

- Early referral of infants prenatally exposed to alcohol to infant development programs and preschools, as they are high risk for developmental delays and problems;
- Early and supportive assistance to the child's family, in particular structured respite services;
- Daily routines and activities that are organized, structured, and predictable for the child;
- Behavioural approach to child management that presents opportunities for the child to experience predictable choices and consequences for behaviour throughout each day (this is not be confused with a traditional behaviour modification approach that is often used for Attention Deficit Disorder).
- Following the child's leads and interests to engage him or her in increasingly longer and more complex interactions with toys, objects and people;

- Teaching the child socially appropriate skills to self-manage behaviours such as temper, impulsivity and hyperactivity;
- Fostering a good understanding for all family members and friends of what can and cannot be changed in terms of behaviour, learning style and memory.

2.3.2.2 A Stable Home and Family Life

The healthy growth and development of children is fostered by a stable, loving and structured home environment. Unfortunately, the reality for many FAS/FAE children is quite the opposite: multiple placements in the child welfare and foster care systems are the norm. To increase the likelihood of a stable family environment:

- Children in care deserve to have contacts with biological parents whose role is supported by the temporary caregiver in non-judgmental ways;
- These children as well deserve to have decisions made early in their life to ensure that they are given secure and permanent homes as soon as possible.

2.3.2.3 Strategies to Improve Educational Outcomes for Young Children

Educators and early intervention specialists are increasingly concerned about finding ways to improve the educational outcomes of FAS/FAE affected children and youth. We have discussed environmental risk factors such as unstable home environments, neglect or abuse, multiple home placements. Another set of risk factors is associated with the attitudes of professionals towards children prenatally exposed to alcohol and other drugs. For example, in a survey of 201 educators in Washington State, 70% believed that students with FAS lived in dysfunctional families. One of the greatest risk factors faced by children is the fear of the professionals working with them. Alcoholism and drug addiction are extremely pervasive and few of us have not been touched by their effects. Confronting one's fears regarding substance abuse and learning about addiction and recovery can be beneficial in working with children and families to provide effective educational experiences for children (Burgess, 1992, p.6).

> *'The truth, however, is that people with FAS/E can only manage the condition. Any changing to be done must be carried out by those who do not have the condition. The changing must be done by the parents, by the educators, by those who make policy, by those who are friends and neighbors of alcohol-affected persons." Brenda McCreight, author and adoptive parent of an FAS child. Recognizing and Managing with Fetal Alcohol Syndrome/Fetal Alcohol Effects: A Guidebook (1997p. 144)*

Some of the strategies identified in the literature are grounded in early childhood education pedagogy, while others are adapted from strategies used in special education. Practitioners have found that children do best when:

- environments are flexible and allow visual stimuli to be regulated according to their abilities to manage such stimuli;
- consistent and nurturing staff who form close bonds with them;

- routines are predictable so as to allow children to "anticipated and manage change"·
- when transition procedures allow them to ease slowly from one activity to another;

Other aspects of sound programming include:

- the use of a wide range of assessment techniques that generate information regarding children's skill levels, coping strategies and learning styles;
- sound and individualized education plans;
- learning environments that enable teachers to meet children's individual needs effectively;
- strong alliances and partnerships between families and schools;
- parent services, including parent education, substance abuse treatment programs, and assistance from social and health services (Brady et al, 1994, p. 45).

2.4 Resiliency and FAS/FAE

Research into protective factors and about building resiliency in children is a recent step forward in the field of prevention and early intervention for at-risk children. This research has begun to reveal the elements, in addition to personal characteristics, that are necessary in families and communities to support and facilitate the development of socially competent children and youth. The current challenge within this work is to appropriately apply and adapt resiliency theories to the reality of individuals, families and communities living with FAS/FAE.

Resiliency is defined as the capability of individuals and systems (families, groups and communities) to cope successfully in the face of significant adversity or risk. This capability develops and changes over time, is enhanced by protective factors within the individual/system and the environment, and contributes to the maintenance or enhancement of health.

Resiliency is not a simple concept. It is not some characteristic that certain individuals do or do not possess. Rather, resiliency must be seen as a complex, dynamic interplay between certain characteristics of "human systems" - which may be individuals, families, neighbourhoods, or communities - and the broader environment that surround the "human system" which changes over time (Egeland et al, 1993; Horowitz, 1987 as cited in Mangham et al , 1995)

The resilient child is characterized as one who "works well, plays well, loves well and expects well". They are portrayed as having attributes in four key areas: social competence, problem solving skills, autonomy and a sense of purpose and future (Bernard, d.u.).

Resiliency research confirms that the quality of the immediate caregiving environment has a significant impact on the well-being and outcomes of children. Families that offer care and support, high expectations, and encourage their child's participation in family life help to foster resilient children.

The family, like individuals, exists within the larger context of communities. For families to create and sustain environments which support resiliency, they must also exist within communities which provide care and support, high expectations and opportunities for participation.

Additional variables also considered as protective factors and important components of resiliency include: coping skills, self-help skills, social support, empowerment, self-esteem, self-efficacy and competence. These variables may work singularly or in concert with each other.

For children with FAS/FAE, the underlying messages of resiliency theory are quite important, that is that affected children will benefit from families and communities which recognize their strengths, offer care and support, have high expectations and encourage their participation. The personal characteristics traditionally associated with resiliency such as social competence, problem solving skills, autonomy and a sense of purpose need to be expanded and reframed for the child with FAS/FAE. Realistic notions of resiliency for the FAS/FAE affected person include behaviours which are adaptive, atypical and may require dependency on others for lifelong support.

Malbin, herself a birth mother, challenges and helps to reframe the current paradigms of resiliency. Malbin advises refocusing our thinking about resiliency in FAS children by starting from the reality that these children are affected by some degree of organic brain damage. She then recommends framing work with FAS/FAE children with the underlying belief that all people always try their best.

Malbin also firmly believes in the identification and nurturing of 'atypical' strengths in people with FAS/FAE in order to foster their resiliency. Based on the contributions of Clarren, Streissguth, Morse, Rathburn, parents and other professionals, Malbin identifies the following characteristics (see Table 4) as strengths often associated with people with FAS/FAE who have had the benefit of early identification and appropriate supports:

Table 4: Common Elements of Strength within the FAS/FAE Child:

- Concrete thinkers
- Strong visual memory
- Kinesthetic acuity, learn by doing, exploring, touching, seeing
- Creative intelligence, artistic and musical
- Use of 'visual' language to communicate effectively, highly verbal
- Perseverative, persistent, committed, enjoys repetitive work, energetic, involved
- Athletic prowess
- Highly moral - deep sense of fairness, rigid belief system, structure dependent
- Strong sense of self
- Friendly - outgoing, gregarious, trusting
- Loving - caring, kind, concerned, sensitive, loyal, faithful
- Affectionate - compassionate, sensitive
- Love and understand children; nurturing and devoted partners and parents
- Tactile
- Good with animals
- Love gardening, constructing and mechanics
- Mechanical Skills
- Spontaneous, curious, questioning, sense of wonder
- Good sense of humour and joyous
- Rich fantasy life, poets, writers, wonderful storytellers

Clearly, many of the above characteristics could by negatively framed as problems. Yet, they may ultimately serve as sources of strength for the individual with FAS/FAE if properly nurtured. Unfortunately, these characteristics may also gradually extinguish or erode without accurate identification and appropriate support. The value in a resiliency focus for FAS/FAE affected people is that it shifts the focus away from pathology, problem behaviours and ill health, toward a focus on building on strengths and supporting protective factors.

Malbin and other advocates for people living with FAS/FAE do not intend to minimize or gloss-over the biological damage done to children by alcohol misuse during pregnancy. Yet, the image of the hopelessly brain-damaged child with FAS doomed to jail is both false and destructive. Intelligent effort by families, communities, human service providers and policy-makers is needed to create a different future for people living with FAS/FAE.

3. Health Promotion and Prevention: Effective Practices and Models

This section of the report discusses effective prevention and intervention practices. A health promotion framework and strategies are reviewed. This framework is consistent with the Framework for Health Promotion outlined by Epp (Achieving Health for All, 1986). Broad-based FAS/FAE prevention strategies are also presented, - the classic framework of primary, secondary, and tertiary prevention.

Many steps have been taken to reduce alcohol-related birth defects since the mid-1970s.Yet thousands of children in the United States and Canada continue to be born each year with FAS/FAE. Given the enormous human and financial costs associated with the primary and secondary disabilities and the life long implications of a diagnosis, fetal alcohol syndrome constitutes a major public health problem. Prevention strategies and their efficacy should be of concern to all.

"It sounds simple: women who drink excessively while pregnant are at high risk for giving birth to children with birth defects. Therefore, to prevent these defects, women should stop drinking alcohol during all phases of pregnancy. Alternatively, women who drink alcohol should not become pregnant unless and until they can control their drinking. More than 20 years ago, when fetal alcohol syndrome was first described in the medical literature, there were high hopes for prevention. In fact, this has not been simple, and the biomedical and public health communities are still struggling to eliminate a birth defect that should be absolutely preventable." (Stratton et al, p. 17).

While there are still many unanswered questions, we now know a great deal about the devastating consequences of this preventable syndrome. The literature clearly indicates the most critical needs lie in the area of strengthening and evaluating prevention efforts.

The most effective way to prevent FAS/FAE is to educate and motivate women to stop consuming alcohol during pregnancies. But prevention of FAS/FAE is more complex than placing all the burden on women to ensure healthy outcomes. The complicated interrelation among alcohol, women, pregnancy, the woman's partner and extended family, the community, and the health care profession means that the prevention of FAS and other alcohol-related birth defects requires a comprehensive program encompassing an array of strategies and approaches (Stratton et al, 1996). Effective primary prevention must address the root causes of several multifaceted public health problems including substance abuse, lack of comprehensive health education, unplanned pregnancy and inadequate pre and postnatal care (Seattle-King County Department of Public Health).

The U.S. Centre for Substance Abuse Prevention found these common characteristics of prevention approaches:

- **prevention must be comprehensive** - a range of services along a continuum of care is needed from before pregnancy to long after pregnancy;

- **prevention should include primary, secondary and tertiary prevention efforts** - primary prevention should not be the exclusive focus; secondary and tertiary prevention are important to prevent another generation of problems;
- **prevention must be collaborative** - cooperation and collaboration among many social agencies and community groups allows for a comprehensive range of services responsive to women and their families needs;
- **prevention must be community-based** - the most effective prevention strategies actively involve the communities for whom the services are intended;
- **prevention must be culturally appropriate** - an understanding of communities' beliefs and values, knowledge and attitudes is important in order to effectively communicate health information in culturally appropriate ways; and
- **prevention must be nonjudgmental and non-punitive** - judgmental and punitive interventions are counterproductive to women seeking services (cited in AADAC, 1996, p45).

3.1 Health Promotion

It is widely recognized in the health promotion literature that fetal alcohol syndrome cannot be separated from the complex social, physical and economic environments impacting alcohol consumption . A health promotion framework or perspective is a common approach to FAS prevention in Canada. It is useful because it broadens and deepens our understanding of the complexities of the problem. It contrasts with a narrow disease-prevention perspective because: (1) it emphasizes the context of individuals' lifestyles, rather than viewing behaviour as simply a personal choice; (2) it recognizes the broad determinants of health such as poverty, violence against women, discrimination and personal barriers to health; (3) it acknowledges the importance of addressing social inequities in health; and (4) it calls for community mobilization and action and coordinated, intersectoral policies to address health issues (AADAC, 1996, Loock, 1994).

American and European studies suggest the major factor associated with FAS/FAE is low socioeconomic status rather than racial background. Studies by Abel (1995) report the risk factors for FAS/FAE are low socioeconomic status, heavy alcohol consumption, smoking, poor nutrition, poor health, increased stress and use of other drugs. In an Alaskan study, smoking status and educational levels were identified as a means for targeting sub-groups at risk for heavy drinking. Canadian data cited 207 cases at the Kinsmen Children's Centre in Saskatchewan where the large majority of children with FAS/FAE have parents with low socioeconomic status.

3.1.1 The Five Components of Health Promotion

The Ottawa Charter for Health Promotion (1986) emphasizes five essential components of health promotion action. Health promotion principles are evident in FAS/FAE initiatives.

1) Build healthy public policy such as warning labels on bottles and banning lifestyle advertising of alcoholic beverages; restricting the availability of alcohol through price increases or increasing the minimum age for drinking; signs in public washrooms and restaurants. An example of such a health promotion activity is The Alcohol Awareness Campaign initiated in 1995 by the BC Liquor Stores, British Columbia Medical Association and BC FAS Resource Society. Campaign materials included a poster, "Alcohol Can Hurt Our Babies", the pamphlet, "Alcohol and Pregnancy" and a press release announcing the program. The participation by all regulated liquor stores (220) is mandatory.

The following countries currently have warning labels on alcoholic beverages: Bermuda, Columbia, Mexico and the United States (all states). The Yukon and the North West Territories have labels which are added at the point of purchase. The province of British Columbia has taken the most action in this area of prevention. The Alberta FAS Provincial Coordinating Committee, chaired by the Alberta Alcohol and Drug Abuse Commission, are reviewing the feasibility of creating public policy in this prevention area (Personal Communication, D. Hermann).

2).Create supportive environments. Women who drink during pregnancy do so in the context of a broader social and familial environment. There is some research to indicate that a father's alcohol use prior to and at conception can also affect the development of a child. Partners share the responsibility for a healthy pregnancy and a healthy baby. There is also a link between violence and alcohol use by pregnant women. Some research shows that women who consume alcohol most heavily during pregnancy are more likely to be in abusive relationships, socially isolated and economically disadvantaged. There is some indication that decreased paternal alcohol consumption during pregnancy assists maternal reduction (Loney et al, 1994).

In light of this information, prevention messages and interventions should not narrowly focus on pregnant or pre-conception women, but also on men. Social supports such as women- and family-centred treatment centres and other resources may also help women reduce their alcohol consumption. Avoiding a narrow focus on prevention efforts with women begins to recognize that in order to prevent FAS/FAE, communities as a whole must change their attitudes and behaviours associated with alcohol.

British Columbia is fortunate to have a network of Pregnancy Outreach Programs and other services for high-risk pregnant women such as Healthiest Babies Possible and Sheway programs. These programs identify women at high risk and provide prenatal support , health care and follow-up services. Program evaluation for the Pregnancy Outreach Programs indicates a significant reduction in the use of alcohol during pregnancy among the nearly nine-hundred program participants to date.

In Prince Rupert, British Columbia, New Beginnings is a residential program for women aged 13 - 24 years who are pregnant or who already have children. Women reside at the program for 18 months postnatal. New Beginnings provides basic living skills, parenting classes, counseling. Many of the residents show signs of FAS/FAE and most of the children display signs of prenatal alcohol exposure, The Infant Development Program works with the women to address early childhood intervention and infant developmental needs.

3).Strengthen community action. Communities across the country are actively involved and committed to addressing the needs of children and families affected by FAS/FAE. Several examples are described below.

The British Columbia Health Promotion Model for Addressing FAS/FAE

The province of British Columbia serves as one model of collaboration between government ministries, programs, and community stakeholders to develop a comprehensive and co-ordinated FAS strategy.

In 1992, representatives from various provincial ministries including the Ministry of Health, Attorney General, Social Services and the Ombudsman as well as key non-government stakeholders from the FAS field developed a strategic plan for addressing the issue of developmental problems related to maternal substance use.

The group identified a core set of goals that individuals, government and non-government organizations could use to address this complex problem. The goals focus on prevention, identification, intervention, evaluation, research and training. The following strategic goals guide the work of British Columbia in addressing FAS/FAE and Alcohol and Drug Related Developmental Disabilities:

1. To identify and reduce the alcohol and other drug-related behaviours that create risk for parents and their children.
2. To reduce the risk factors that compound the effects of using alcohol and other drugs in pregnancy including family violence, poverty and poor nutrition.
3. To improve and increase early identification of individual children and families who have been affected by prenatal alcohol and/or drug use.
4. To develop and support appropriate intervention and management for children and families affected by FAS and other Alcohol and Drug Related Developmental Disabilities.
5. To ensure educational strategies are targeted.
6. To contribute to the development of supportive environments through public policy that is conducive to good health and encourages healthy children, families and communities.

Based on the above strategic goals, action has taken place within five distinct areas of focus:

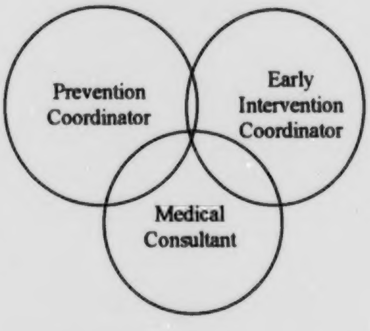
1. Health Promotion and Prevention
2. Early Identification and Clinical Services
3. Integration of Services
4. Focused Research
5. Provincial Coordination including:
    - co-ordination of community-based prevention and early intervention program development,
    - implementation and evaluation;
    - co-ordination of regional medical consultants;
    - inter-ministry co-ordination of the funding and delivery of service by government ministries;

As a result of the strategic plan, three positions were established, a FAS Prevention Coordinator, a FAS Early Intervention Coordinator and an FAS Medical Consultant. These positions are funded through the BC Ministry for Children and provide Province-wide coordination of health promotion and primary, secondary and tertiary prevention on FAS. The following graphic illustrates the coordination of primary, secondary and tertiary prevention of FAS funded through the B.C. Ministry for Children and Families.

TABLE 5

Primary Activities:
- promotes and supports a network of information and expertise on FAS/ ADRDD prevention amongst FAS programs and projects throughout the province
- initiatives to enhance training opportunities about FAS/ ADRDD for community groups
- provides info and referral services for the public on how to access information, resources, expertise and services related to FAS
- designs a community-based process for engaging communities in policy development about FAS/ ADRDD

.9 FTE



Primary Activities:
- works with health/social service providers towards the provision of improved early intervention approaches with women at risk
- develops media strategy and policy work on legal actions regarding appropriate and accessible treatment for women using alcohol and other drugs during pregnancy
- gathers and disseminates info on effective,early intervention strategies
- promotes networking and joint planning amongst FAS programs and those doing women's health promotion throughout BC

.9 FTE

Primary Activities:
- acts as a resource on FAS to health and health care organizations
- works with UBC on education of medical students and BCMA on continuing medical education
- liaises with provincial and federal governments on policy, research and prevention strategies
- provides clinical expertise, diagnosis and early intervention for people affected

Contracted Services

Source: The British Columbia FAS Strategic Plan Report (Draft Document), 1997.

The goal of FAS coordination services in BC is to stimulate collaborative, systemic change towards the prevention of FAS/ADRDD and the amelioration of secondary disabilities for affected families and individuals.

This type of comprehensive, coordinated and community-based approach is supported throughout the health promotion and prevention literature. It is also strongly supported by the research of Streissguth and others in their recommendations for addressing the complex needs and issues surrounding individuals, families and communities affected by FAS. A wide spectrum of people, agencies, institutions and government departments are involved with FAS issues. To be successful and effective, primary, secondary and tertiary prevention and health promotion strategies must be integrated and comprehensive.

The Saskatchewan Experience

Saskatchewan has been addressing FAS through research, policy and program development since the mid 1970s. The first diagnosed case of FAS in Canada was made at Royal University Hospital, Saskatoon in 1975. Research projects have been conducted at the Alvin Buckwold Child Development Program at the Kinsmen Children's Centre. A multidisciplinary FAS team is in place at he Centre, providing diagnosis, assessment, treatment and support for children and families affected by FAS. The Saskatchewan Institute on Prevention of Handicaps identified FAS a major program focus in 1985. The Institute has sponsored Public Service Announcements, hosted a FAS Conference in 1985, conducted research with pediatricians and family practitioners to determine their level of awareness of FAS, developed and disseminated over 2000 information and education kits and has produced a video "A Precious Gift". This video is a 16 minute video, filmed on the Beardy's and Okemasis Reserve in Saskatchewan. The Precious Gift video is culturally sensitive and appropriate and is ideal for professionals working in the area of public health, education, and social services. The role of the extended family, community, friends and community is emphasized as critical to helping youth and young adults make healthy decisions about their drinking behaviours.

It wasn't until 1993, that a provincial interagency committee was established to assist in the coordination of prevention efforts. The Fetal Alcohol Syndrome Coordinating Committee initiated a needs assessment and symposium in 1993. A result of the symposium was the establishment of working subcommittees in the areas of education, justice, health, parents/community, and social services. These committees identified the need for a renewed commitment and approach to prevention based on health promotion and community-based programs. An FAS Provincial Coordinator, located at the Prevention Institute has been in place since 1996.

The Saskatchewan Institute for the Prevention of Handicaps coordinates a recent province-wide initiative on FAS. Announced in 1996, through the Ministry of Health, the initiative focuses on the prevention and intervention with individuals and families affected by FAS. The thrust of the initiative is community mobilization and action towards changing behaviours. Communities will be assisted (seed grants of $7,000.) to build on existing capacities and resources. The plan stresses consultation with key stakeholders and an intersectoral approach. **A province-wide, collaborative and coordinated approach appears to be the most effective strategy that is supported by the literature and duplicated in other jurisdictions.**

Despite substantial prevention and education efforts about FAS in Saskatchewan over the last 20 years, its incidence rate has not decreased. According to a 1996 report, the rate remained relatively unchanged from 0.515 per 1000 live births in 1973-1977 and 0.589 per 1000 live births in 1988 - 1992. The study calls for new approaches to reduce the incidence of FAS and to place emphasis on counseling high-risk women and community development programs (Habbick, et al, 1996).

Primary prevention is a central feature in an over-arching prevention framework, however, the research cautions strongly against a unidimensional approach. The findings from the Saskatchewan study point to the inherent limitations of "putting all your eggs" in one basket by over-reliance on traditional prevention strategies.

Manitoba Initiatives

The Committee on Alcohol and Pregnancy was established by the Manitoba Medical Association in 1993. It is an inter-disciplinary committee responsible for developing an FAS/FAE Network throughout the province, and promoting initiatives regarding FAS/FAE in Manitoba. The committee includes birth, foster and adoptive parents and professionals from health, social services, education and corrections fields. Membership also includes representations from the Aboriginal community and person working in the addictions area. A working group and sub-committee model is employed to develop and implement primary prevention, research, a series of booklets for caregivers, guidelines for diagnosis and treatment.

Manitoba also has a Fetal Alcohol Support Network for caregivers and families with FAS/FAE children. Located in Winnipeg, the Inter-agency FAS/FAE Prevention and Intervention Program provides early identification and intervention services for children and their families. Staff of the agency provide training and support for caregivers. The agency has a prevention program targeted a high-risk women of childbearing years.

The FAS Outreach Team provides services to children, from birth to Grade One who have been diagnosed with FAS/FAE and who live in Winnipeg. The inter-disciplinary team provides: behavioural and developmental services to children in their homes, daycares, and schools; support to families and caregivers of children with FAS/FAE; public and professional education; case coordination; community liaison; and short-term consultation with other agencies. Occupational, physical and speech therapy consultation is offered by a collateral agency in the city (Lutra, 1996).

Northern Initiatives

Sioux Lookout FAS/FAE Prevention and Support Services Program is located in northern Ontario. The FAS/FAE Prevention and Support Services Project is sponsored and delivered by the Patricia Centre for Children and Youth. The project is focused primarily on the communities of Sioux Lookout and Red Lake, and to a lesser extent on the surrounding region of northwestern Ontario. It is funded under Health Canada's Community Action for Children Program for the period June 1994 through March, 1998 (Evaluation Project Report, 1998).

The CAPC program is a community-based initiative which seeks to undertake a range of FAS/FAE prevention activities. The goals of the program are two-fold: 1) to reduce the incidence of FAS/FAE cases and alcohol affected pregnancies among community residents in Sioux Lookout and Red Lake and promote the growth of healthy parents and babies; and 2) to determine the extent of FAS/FAE cases and alcohol affected pregnancies with the service region.

Yellowknife is a community with growing awareness and services for children and families affected by FAS/FAE. The Yellowknife Association for Community Living advocates on behalf of and assists intellectually disabled people and operates the FAS/FAE Family Support Program. The Support Program is a community-based outreach program which takes a family-centred approach to helping families with FAS/FAE children. The program offers respite, home visiting, parent support groups, education, referrals, and advocacy. The Family Support Program also offers recommendations to governments and other agencies. The program works closely with other services in the community such as the Toy Lending Library and the Yellowknife Women's Centre. Most recently, the Yellowknife Association for Community Living produced an excellent video entitled "Helping Families - Helping Children". A companion guide is scheduled to be ready in mid- 1998. A new coalition of agencies in Yellowknife call themselves "Coalition for New Futures for Northern Women" is recently formed. The Coalition intends to build on the exciting initiatives underway in the North West Territories, and to expand treatment and after-care services for pregnant and addicted women.

The Yukon Association for Community Living commissioned a qualitative study to determine the needs of people with FAS/FAE. The study concluded that a systemic plan of prevention which incorporates a number of formats and responses is required and must be implemented within the community with assistance from a coordinating body or person.

The Pauktuutit Inuit Women's Association with the National Inuit Working Group for FAS published A Community Perspective on Health Promotion and Substance Abuse (1993) to help communities understand FAS and what they can do to help. The National Working Group includes representation from the Baffin, Keewatin, Kitikmeot, Inuvik and Northern Quebec regions. The resource guide is a good example, of linguistic and culturally appropriate materials developed by the people understand the contextual complexities of the communities that they work and live in. It is wonderful example of women taking leadership and action towards preventing FAS and promoting community healing.

4).Develop personal skills, and 5). Re-orient health services

Effective community actions combine activities which aim to increase healthy behaviours and resilience factors with those which aim to reduce behaviours which create risk for the mother and unborn child. Activities intended to change factors in the cultural, community and social environment which maintain the problem such as poverty, discrimination coupled with activities intended to change the knowledge, skills and attitudes of individuals are also likely to effective in preventing FAS. British Columbia's Crabtree Corner is an example of such a comprehensive approach.

YWCA Crabtree Corner FAS/FAE prevention project is a community-based program located in the downtown eastside of Vancouver. Originally funded by Health Canada for three years, the program is now funded primarily by the British Columbia Ministry for Children and Families. Started in 1987, Crabtree Corner was the first federally-funded FAS prevention program in Canada. Most of the women that reside in the downtown eastside and access the services of Crabtree Corner, are extremely socially and economically disadvantaged. Many are homeless or marginally housed, living on the margins of mainstream society. The majority of women suffer the effects of childhood physical and sexual abuse, partner violence, poverty and discrimination. Many of the women are adults suffering the effects of fetal alcohol exposure; often struggling to raise children also affected by maternal alcohol use. Multiple risk factors and health problems such as multiple partners, injectable drug use, alcohol abuse put them at a high risk for HIV infection, hepatitis, sexually-transmitted diseases, tuberculosis and a plethora of other health problems.

The program offers a range of services to women and children, including a drop-in daycare for children 6 weeks to six years of age. Many of the children are fetal alcohol affected. The staff offer support, counseling and intense advocacy services for clients.

The program is also very active in addressing systemic issues such as poverty, racism and violence against women. They work in coalition with other advocacy and social change organizations, act as local and national consultants, and lobby for legislative and healthy public policy development such as bottle labeling and warning sign legislation and primary prevention initiatives. Along with other members of an FAS prevention advisory group, Crabtree Corner has fought for a continuum of comprehensive programs for women and children at risk of experiencing the effects of prenatal alcohol and other drug exposure.

The Crabtree program is an innovative, culturally-sensitive program serving the needs of extremely high-risk women and children in one of Canada's most impoverished neighborhoods. A notable strength of the Crabtree program is the emphasis on action and social change. Crabtree operationalizes the principles and philosophy of health promotion by involving community and those targeted by the program. Crabtree recently participated in the making of a video entitled ***"Mothers Choice"*** about Aboriginal women and their stories of struggle and hope surrounding FAS. It is a powerful reminder of the complexities of women's lives and their courage to change.

"Sheway" is a Coast Salish word that means "growth". Sheway is a collaborative project which involves a number of agencies, including YWCA'S Crabtree Corner, Vancouver Native Health Society and the Vancouver Health Department. Sheway recognizes that the health of women is linked to the social and economic conditions of their lives and their ability to influence these conditions. The Sheway program also located in the inner city of Vancouver serves approximately 100 women per year - all clients are high-risk for alcohol and drug abuse. 46% of the population of the downtown eastside of Vancouver are identified as having a high risk of serious prenatal alcohol or drug exposure (Whynot,1994).The program offers comprehensive prenatal and postnatal outreach services and recently added outreach medical services including nursing, midwifery and pediatric care.

A program with a similar philosophical and practice framework to Crabtree Corner is a Health Canada funded program in Toronto, called "Breaking the Cycle". This program is a collaborative partnership between the Canadian Mothercraft Society, Jean Tweed Treatment Centre, MotheRisk, Hospital for Sick Children, Metro Toronto Children's Aid Society and the City of Toronto Department of Public Health. "Breaking the Cycle" is an education, prevention and early intervention program for pregnant and parenting women abusing alcohol and/or other drugs. The program reaches an extremely high risk population of women and young girls. The programs goals: reduce harm to children by helping moms reduce or eliminate drug and alcohol use while they develop good parenting skills. Breaking the Cycle is an innovative, harm reduction approach to prevention and intervention utilizing the skills, infrastructure and resources of multiple systems of care. The program provides:

> *"Drinking during pregnancy is linked with disaster - - personal disaster for the "bright-eyed ones," disaster for their families and their hopes, for their young, and disaster for all segments of our society as we struggle to pay the huge price of this destruction. We, as a society, suffer when we produce children with disabilities, and we as a society pay the costs... when we fail to prevent FAS." Streissguth, 1997, p 280*

- medical services for women and their children
- education/prevention on the risks of alcohol and drugs to the unborn child;
- help to address substance abuse and/or recovery needs;
- prenatal care;
- child development and parenting skills;
- personal counseling; and
- a clothing exchange.

It should be noted that this approach based on a harm reduction model has been adopted in the North West Territories by the Yellowknife Women's Centre which offers similar supports to pregnant and parenting women (Lutra, 1996, p.34).

3.2 Public Health Model of Prevention

The public health model of FAS/FAE prevention emphasizes that all social institutions can be potential agents of change and can affect individual and group behaviour. Stratton et al, 1996, recommend that a comprehensive FAS prevention program should provide multiple and overlapping levels of reinforcement, incentives, and controls. Prevention efforts are best aimed at women, their partners and families. Many prevention projects also entail community support and general programs to decrease risk factors for alcohol use and increase protective factors against alcohol misuse.

Streissguth (1997) emphasizes the **5 Ps of Prevention**:

- public education
- professional training
- public policy
- programs and services
- parent and citizen activism

Streissguth (1997) writes "No one of these prevention arenas can, by itself, prevent all alcohol-related birth defects. Yet, together they can work to substantially reduce the risk of FAS and other types of prenatal alcohol damage to children." This report will focus on public education, professional training and effective prevention programs and services for high-risk pregnant women. Public policy issues are discussed briefly throughout this document.

1. Public Education - Public education can be considered the cornerstone of all FAS prevention efforts. Only an informed public will buy into and participate in a comprehensive and coordinated (and perhaps costly) FAS prevention strategy. Public education is a primary prevention or universal prevention intervention directed to the general public or to an entire population group that has not been identified on the basis of increased risk. Interventions tailored specifically to pregnant women or preconceptional women fall into this category (Stratton et al, p. 116).

Television advertisements, public service announcements, pamphlets, posters are examples of primary prevention communication strategies. Laws and regulations that attempt to change the social environment and discourage drinking are also examples of primary prevention. Efforts to improve the social and economic status of women or the entire population could also be considered universal prevention as the research indicates that higher socioeconomic status, education, and access to meaningful employment are influential in decreasing alcohol misuse and, therefore may lower FAS outcomes among women (Stratton et al, 1996 p. 116).

The following is an example of a primary prevention message:

When pregnant, or planning to become pregnant, it is best not to drink alcohol. (Health Canada)

There is no known "safe" pattern or level of alcohol consumption during pregnancy. It is not clear whether there is a threshold amount of alcohol that must be consumed before damage to the baby occurs. Nor is there scientific proof that small amounts of alcohol are safe. The majority of researchers recommend complete abstinence or at least reducing intake to minimal levels. Even further, some also advise that women who are planning a pregnancy and nursing mothers abstain from alcohol.

The universal prevention message of FAS is a prudent and conservative one that encourages abstinence prior to conception and throughout pregnancy.

Health care providers and social service agencies should engage in primary or universal prevention strategies. CAPC and CPNP programs are well-positioned to deliver FAS prevention messages. Posters, pamphlets, parent education, contact with public health officials are potential activities. CAPC and CPNP programs are multi-dimensional and offer prenatal nutrition and pregnancy and parent outreach programs to an at risk population. Many opportunities exist to imbed FAS primary prevention messages and support. Pamphlets and posters alone may have limited impact with high-risk women who are socially and economically marginalized - genuine support that is non-judgmental and consistent is more likely to have a positive impact.

Decreasing risk factors and increasing protective factors for alcohol use in general is the overall goal of universal prevention. Male partners, extended family members, peers and service providers could play a vital role in reinforcing a prevention message and encouraging positive attitudes and behaviours.

There is no research data found that demonstrates a change in the prevalence of FAS in response to universal prevention efforts. As discussed above there is no national incidence or prevalence data of FAS in Canada. Studies from the National Health Interview Survey in the U.S. indicate a statistically significant increase between 1985 and 1990 in the number of people ages 18 - 44 who had heard of FAS, who agreed that heavy drinking during pregnancy carries risks, and who could correctly identify FAS as a birth defect (Dufour, 1994 as cited in Stratton et al, 1996).

2. Professional Training - Prevention efforts should focus on training and educating a wide range of professionals, including, health care workers, teachers, social service personnel, early intervention specialists, criminal justice workers and substance abuse counselors. An important measurable outcome of these efforts is in the increase in the number of professionals who consistently and clearly recommend abstinence during pregnancy.

The establishment of the FAS Information Line of the Canadian Centre on Substance Abuse (funded by the Distillers Association of Canada) is a widely used service by professionals from all fields. All Canadians can access the line through a 1 -800 number. The BC Prevention Resource Centre has an impressive collection of resource materials and references on FAS/FAE. A 1-800 number has also been established by the Ministry of Education to assist teachers, teachers' assistants and principles with inquires about FAS/FAE. An "FAS Resource Guide to Support Teachers" became available in 1996. Alberta's Ministry for Education (Special Services Branch) has recently developed a similar resource for educators. AADAC distributes an excellent manual (1996) on FAS/FAE. Alberta Family and Social Services in Lethbridge has dedicated one staff position as an FAS trainer within the province of Alberta. Private consultants and trainers, such as Mary Vandenbrink from Edmonton and Dr. Valerie Massey are available for FAS/FAE education and training.

Assessing risk during pregnancy is an essential step toward educating pregnant women about the dangers of drinking during pregnancy. The physician and other primary care health providers can play an important role in the identification of alcohol-related problems in women. Routine pre- and postnatal visits provide multiple opportunities for women to ask questions and for health care providers to give information and address the health concerns that may put them at risk for a less than optimum pregnancy. Health care providers need to take a proactive approach with all pregnant women. Several screening tools are available to help identify women who potentially have a problem with alcohol.

The three most commonly cited brief questionnaires used to identify at-risk women for heavy drinking are the T-ACE, the CAGE and the TWEAK tests. The TWEAK questionnaire was developed by Dr. Russel at the Research Institute on Addictions in Buffalo New York (AADAC, 1996, p.39). TWEAK combines questions from the MAST, CAGE and T-ACE tests that have shown to be most effective in early identification of high-risk women. The TWEAK includes five questions, and like the T-ACE a total score of 2 or more indicates high-risk drinking.

The TWEAK Test
T How many drinks can you hold (Tolerance)?
W Have close friends or relatives Worried or complained about your drinking in the past year?
E Do you sometimes take a drink in the morning when you first get up(Eye-opener)?
A Has a friend or family member ever told you about things you said or did while you were drinking that you could not remember (Amnesia)?
K Do you sometimes feel the need to Cut Down on your drinking?

The T-ACE test is a screening tool for identifying risk drinkers. The Tolerance question is scored as 2 points if the respondent reports needing more than two drinks to get high. The other questions are scored as 1 point each for a positive answer. Scores of 2 or more are considered evidence of risk drinking.

The T-ACE Test
T How many drinks does it take you to get high (tolerance)?
A Have people ever annoyed you by criticizing your drinking?
C Have you ever felt you ought to cut down on your drinking?
E Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover?

For many women receiving information about the risk involved and advice about drinking are sufficient to motivate them to abstain from consuming alcohol during pregnancy. However, more intensive intervention is required for pregnant women who drink heavily and are unable to reduce their alcohol intake. Treatment and addictions services for pregnant women are lacking in most communities, however, it is still important to have effective links between the health care and addictions treatment programs (AADAC, 1996).

Health care providers administer the screening test to pregnant women. The Canadian Periodic Health Examination supports the recommendation that screening and counseling be included in all routine health examinations of pregnant women. The T-ACE test is administered in all Pregnancy Outreach Programs, Crabtree Corner, Sheway and other outreach programs targeted at high-risk women in British Columbia.

3. **Programs and Services** - Alcohol is an addictive drug (AADAC, 1996.) Research indicates that women face many personal and systemic barriers to entering addictions treatment. There is tremendous stigma attached to being pregnant and addicted to alcohol or drugs and often there is failure on the part of addiction agencies to recognize or meet the needs of women and particularly pregnant and parenting women. Fear of losing their children or placing children in temporary care of the state is a deterrent for help-seeking behaviour.

If communities are to prevent fetal alcohol damage to children, they must begin by extending services to high-risk women and birth mothers that focus on reducing alcohol intake, increasing family planning, advocating for the mothers and ensuring safety for the children (Streissguth, p. 264). The most exemplary example of this philosophy and approach can be found in Seattle, Washington. Known locally as the "*Birth to 3" project, the Seattle Paraprofessional Advocacy Program* was created to identify mothers at high risk at delivery, to intervene with these mothers after the birth of their children, and to help this population of women who so often "slip through the cracks.". The program seizes the opportunity when the most high-risk women enter the health care system.

The Birth to 3 project provides long-term advocacy for three years for birth mothers and their infants. Project goals are: 1) to prevent fetal alcohol and drug effects in children; 2) to help these children be raised in a healthy environment by their families, and 3) to help birth mothers resolve alcohol and drug problems and develop healthy, productive lifestyles. The women who take part in the program are typically poor, marginally housed or homeless, chronically unemployed, history of abusive and dysfunctional relationships with men and their families. Each woman is paired with an advocate/case manager whose role is to help address the problems as identified by the mother as the most urgent.

A number of successful intervention programs for high-risk women and their children share common principles and strategies:

- **coordinated team case management and strong referral relationships between social, health and child welfare services;**
- **a family-centred approach incorporating home visiting;**
- **improvement of social and physical environments such as housing and support networks**
- **utilization of substance abuse treatment programs tailored for women and their children**

Incorporating FAS interventions during pregnancy into existing services systems may be cost-effective and creative approach to prevention. Utilizing existing expertise and programs that connect with pregnant women is a logical intervention strategy. CPNP is a prime example of such an opportunity. It is important that women be approached with the attitude of helpfulness and support. It is very counter-productive to make pregnant women who drink feel shamed or blamed; it is highly likely that these high-risk women will avoid health care professionals and "go underground" from those they deem judgmental of their behaviours and lifestyle. This is particularly salient for the most high-risk population, such as prostitutes, homeless women and street youth.

4. Parent and Citizen Activism -All parents need connection with the broader community and to feel supported by services and systems. Parents of children affected by FAS/FAE often require support and acknowledgement from other FAS parents. Support and advocacy groups foster successful parenting through:

- Exchanging ideas and learning about FAS/FAE.
- Ensuring that the basic needs of family members are met
- Providing parents with knowledge of child development and behaviour to help them to recognize the unique pattern of each individual child
- Ensuring that appropriate assessments, diagnoses, and interventions are provided
- Designing interventions that are family-centred and that provide parents with specific skills in behaviour management
- Providing knowledge of community resources and assistance to access services
- Providing access to respite, counseling, and emotional support that addresses early losses or childhood abuse, as well as guilt about the FAS/FAE diagnosis
- Assisting families to become an effective advocate for their children

(Source: B.C. FAS Community Action Guide, 1997).

Not surprisingly, parents of children with FAS/FAE often have strained relationships with professional systems. The view from the parent perspective is clearly different than the view from the professional perspective. Somehow, if the needs of the child with FAS/FAE are to be better served, these viewpoints must find common ground. The investment of the professional service provider is time limited, while the investment of the parent is for life. Finding common ground is never an easy process and usually requires greater investment of time and persistence by the parent. Thus, the parent of an FAS/FAE child, in many ways, has little option in becoming an advocate for their child.

Parents Want to Feel...

- *Valued as individuals and as parents with strengths*
- *Listened to and heart*
- *That they are regarded as an expert on their child's needs*
- *Involved in a meaningful way*
- *Less Guilt*
- *Less Blame*
- *Informed and Knowledgeable*
- *Confident*
- *Proactive*
- *Assertive*
- *Hopefulness for their child's future*

Throughout the literature the need for a lifetime advocate or "external brain" is mentioned. Jan Lutke eloquently explains that the decision to become an advocate "arises out of the love you feel for your child and the pain you experience as you watch your child struggle everyday in a world he does not understand, with expectations he cannot meet, and which turns him into a "bad" person when he fails." (Fantastic Antone Succeeds, 1993, p.93). She further notes that advocacy gives the parent some measure of control over their child's live as well as the knowledge that the situation is not hopeless and the parent and child is not helpless.

What is an advocate? An advocate is an active mediator between the person with FAS/FAE and the environment. An advocate helps interpret the child to the world and the child to herself. The advocate is a key figure in preventing or ameliorating secondary disabilities that can truly change the life trajectory of individuals with FAS/FAE.

Special Needs Adoptive Parents (SNAP): This society provides high quality educational services to professionals, parents and support groups throughout British Columbia. They facilitate 18 parent support groups throughout the province and recently developed a parenting guide, entitled "FAS/E: Parenting Children with FAS - A Guide for Daily Living". SNAP also provides information services through their extensive library holdings.

B.C. FAS Resource Society: The FAS/E Support Network is a parent support program, which provides training, information, consultation, and a "warm-line" for birth, foster, adoptive as well as for other caregivers and professionals. The agency has developed as series of layman's guides to FAS/FAE, assessment tools and guides to the education system. Trainers form the B.C. FAS Resource Society conduct in-depth training across North America.

The preceding literature review and description of effective practices serves as a foundation for understanding the medical and sociological complexities of FAS/FAE. It is evident from a review of the literature that practitioners have a wealth of information to inform their practice. Early interventionists, educators, community developers, medical and health practitioners, children and families also have much to offer academic and scientific research. It is extremely imperative and helpful when wisdom and knowledge are shared for the betterment of children and families affected by FAS/FAE. Although small in scale, it is our hope that the findings from the literature review and the pilot studies reinforce and reflect this belief. The following section of this document describes the findings and recommendations from the FAS/FAE pilot projects in Lethbridge and Fort McMurray, Alberta.

4. Evaluation Approach

To evaluate the management, process, outputs and initial outcomes of the FAS/FAE Pilot Project, a multifaceted approach was used. A summary of the data collection methods follows. A detailed Evaluation Plan is found in Appendix B.

4.1 Document Review

In collecting data for the evaluation, there a wide variety of documents were reviewed., including previous CAPC evaluations, program materials supplied by the sites, committee minutes, site work plans and workshop participant evaluations.

4.2 Site Visits

Site visits allowed the evaluator the opportunity of observing program components first-hand. The specific information gathered from such visits was guided by a Framework for Data Collection found in Appendix C. Additionally, site visits allowed for the face-to-face interviewing of local key informants. Project consultants made two visits to Fort McMurray and three visits to Lethbridge. The evaluator made one visit to Fort McMurray and two visits to Lethbridge.

A training workshop in Maple Ridge, BC held in January, 1998, was attended by two project consultants, and personnel from Health Canada, both pilot sites, and the project sponsor, The Candora Society. This workshop participation allowed personnel from both sites to meet each other and also to discuss relevant issues among themselves and with the consultants and Health Canada staff.

4.3 Key Informant Interviews/ Focus Groups

Face-to-face and telephone interviews were used to collect information from key informants in each site and from others related to the project. Key informants included pilot site project personnel, local social services and health care providers, FAS Working committee members in both cities, adoptive parents, advisory committee members and personnel form Health Canada and Equitable Consulting Services. The Framework for Data Collection (see Appendix C) and guiding questions were used to structure the interviews (see Appendix D). A list of all key informants is appended (see Appendix E).

5. Baseline Data

Baseline data related to the two pilot sites was collected through site visits and telephone interviews, in December, 1997, prior to the commencement of project activities.. This approach allowed for triangulation of data collection to validate information received. The collection of data prior to the commencement of project activities was designed to provide a baseline against which future comparisons could be made. It was anticipated that implementation of project activities would, over the long-term, result in changes in behaviours, capacities, resources and services that could be compared to the baseline data descriptions. Follow-up studies would then be able to compare data collected at a later date with the baseline data to describe results of this and future projects. The following descriptions of the two pilot sites summarize the information gathered from all sources.

5.1 Fort McMurray Children's Centre

Fort McMurray is a city of approximately 45,000 people located 560 km north of Edmonton. Two large oil sands projects attract a young and transient population without traditional family supports . Additionally, Metis and Aboriginal communities surround the city. Socio/demographic issues identified by respondents included:

- Lack of affordable housing;
- High risk behaviours: unprotected sex, high alcohol consumption, particularly weekend binge drinking; and
- Isolation, both geographic and familial.

5.1.1 Current Program

The Children's Centre was born of the recognition, by a local group, of a gap in services available to young at-risk children and their families. The Children's Centre is supported by five different funding sources and employs fifteen staff. The Children's Centre does not have its own site but partners with four different organizations to house it. The current housing arrangement with the Father Turcotte School will end in May, 1998. Additional sites include the Boys and Girls Club, the school in Ft. McKay and a Band owned building at Gregoire Lake. Since its inception in 1993, the Children's Centre has grown to include 6 full-time programs:

- **Family Visitor/Outreach worker**: is a family-centered program that assists families with children ages 0 to 6 years with support in their homes. Family visitors provide help and education with parenting issues, help parents access community resources, provide information and education related to child health, nutrition, home management, communication and problem solving and provide advocacy to parents as needed. Family visitors also can facilitate collective kitchens and Nobody's Perfect Parenting programs. Families enter the program through self-referral or referrals by community members and agencies, including other Children's Centre staff. Aboriginal family visitors are also available for aboriginal families requesting this service.

- **Pre/post -Natal Nutrition Program**: operates two days per week, providing information and consultation relate to nutrition, focusing on pre/post natal nutrition. The Collective Kitchen program is a component of the pre/post natal nutrition program.
- **Collective Kitchen**: New groups start every three months to provide the opportunity for participants to cook wholesome, nutritious food together and also have the opportunity to make new friends and save on their food budgets. Each group meets three times per month. One meeting is to decide on the recipes, a second meeting is devoted to shopping for the ingredients and the third is to actually cook the meals. At each Collective Kitchen, the group makes five different meals for themselves and their families. The meals cost $1.00 each, therefore a family of three would pay $15.00 for 15 meals which would be one meal per day for each of the three family members for 5 days.
- **Multicultural Pre-school**: provides an opportunity for children aged 3 to 5 years to get a headstart before entering the school system. The program focuses on thinking and problem solving, with a focus on the development of language skills, and nurturing a strong sense of self-esteem within each child. Four sessions are available, including both morning and afternoon programs. There are spaces for twenty-four children in each session. The goal of the program is to reserve 18 out of 24 spaces for children in their primary target group, with the reaming spaces open. Children in the primary target group are in families with one or more of the following characteristics: mother less than 20 years old, lone parent, low income, Aboriginal, recent immigrant, transient between their reserve or settlement and Fort McMurray or involved with child welfare. Fee and transportation subsidies are available.
- **Rural Outreach Pre-school Program**: provides a similar preschool program with one class in each of Ft.. McKay, Gregoire Lake, and Janvier.
- **Parent-Toddler Drop-In Centre**: provides a place for parents and their children 0 to 3 years to meet informally. A facilitator trained in early childhood development is available. A safe and friendly playroom especially developed for toddlers is available. Child development material is available. There are two sessions per day, three days per week.
- **School Mentor**: works half time with preschool graduates now in the school system, to ensure continued follow up and advocacy for these children.
- **Nobody's Perfect Parenting Programs**: are offered several times per year by the outreach family visitors.

5.1.2 FAS in Context

The Children's Centre preschool and rural preschool programs currently include 85 children. Of these 85 children, 3 children have an official diagnosis of FAS (3.5%). These children were diagnosed in Edmonton at the Glenrose Hospital. Centre staff suggest that an additional 10% have undiagnosed FAS. Also another 5% are diagnosed with *Oppositional Defiant Disorder*. In the broader context of Fort McMurray, Handicapped Children's Services includes 15 children with a confirmed diagnosis of FAS on their caseload. This agency only works with children who have a medical diagnosis of FAS. Community Mental Health does not require a diagnosis to work with children. They also noted that FAS would not qualify, if a diagnosis were needed, because it is not included in the DSM-IV. Unofficially, Community Mental Health staff suggests that between 50-75% of the children that they see in child/family counseling have some degree of FAS. Although FAS crosses all socio-cultural boundaries, informants report that of the children they see, there appears to be a higher incidence in Fort McMurray among the aboriginal population.

It is not possible to make firm statements of incidence or prevalence because no clear tracking or surveillance methods are in place at either the regional health authority or provincial level. The lack of diagnoses, substitution of behavioural diagnoses and cross-over of clients makes even a "guesstimate" highly unreliable.

5.1.3 Current Diagnostic Procedure

In order for a child to be diagnosed with FAS/FAE, they must travel out of Fort McMurray, usually to Edmonton's Glenrose Hospital to be assessed, often over 3 to 5 days. Alberta Family and Social Services do not pay for travel or the costs of an assessment. The financial implications are reported to constitute a barrier such that many children do not have an official diagnosis. There are two pediatricians in Fort McMurray who do not diagnose FAS/FAE. A psychiatrist visits Fort McMurray twice a month. Wait lists are up to 6 months for an urgent consultation with this psychiatrist. This psychiatrist does not diagnose FAS/FAE, but as opportunity arises, provides assessment, medication orders and follow-up for secondary mental health or behaviour disorders..

Several agencies suggested that parents might not bother with the cost and process of gaining a diagnosis because it is not seen as leading to better outcomes for their children. Children diagnosed with FAS/FAE do not qualify for a 1:1 aide in the school system under current Alberta Education Program Unit Funding (PUF) grant guidelines. The practice, therefore, is that children are given a diagnosis related to behavioural problems, such as *Oppositional Defiant Disorder*, rather than the underlying pathology. Behavioural diagnoses are eligible for PUF grants for additional educational support or 1:1 aides in the classroom.

There was also a concern expressed that medical professionals are reluctant to tell parents, that their child has FAS/FAE. Children are then diagnosed with behavioural terms that do the child an injustice because they set up the expectation of improvement, which will not come if the underlying pathology is FAS/FAE. One respondent stated that " ADHD is just a nicer name for FAS in this community".

5.1.4 Current FAS-specific programming at The Children's Centre

There is presently no specific programming for FAS at the Children's Centre. Teachers in the pre-school programs know that children with FAS/FAE require structure and a longer period to anticipate, prepare for and make transitions within the daily schedule. Informal teaching for parents and caregivers related to FAS/FAE prevention and the impact of pre-natal exposure to alcohol is done as the topic arises in various program areas such as the Drop-In Program and Prenatal Nutrition Program. There are also no formal support programs directed at parents of children with FAS/FAE offered by the Children's Centre.

The environment of the pre-school program may also, unwittingly be compounding problems for those children with FAS/FAE. The pre-school environment is highly stimulating, with a variety of pictures, posters, and colors, all very appropriate for enriching pre-schoolers. However, for children with FAS/FAE, the large amount of stimulation may in itself be so distracting that their ability to attend is significantly diminished (Kvigne, Struck, Englehart and West, 1997)

Children's Centre staff identified that increased knowledge, training and resources would enable them to develop FAS/FAE-specific programming.

5.1.5 Current Community FAS Programming, Services and Resources

None of the informants from Fort McMurray identified any formal programs, services or resources specific to FAS/FAE. FAS was suspected by social services and mental health informants as the underlying reason for individuals' contacts with social agencies, but services provided were generally for a secondary reason, such as behavioural problems.

Programs/Services
Community Mental Health provides individual and family psycho-educational counseling for secondary mental health disorders and conduct disorders including ADHD, to children over the age of 5 years through the Parent-Child Resource Centre. The Parent-Child Resource Centre, based in the Fort McMurray Hospital provides in-home behavioural assessment and intervention based on a behaviour modification model to children under 5 years of age. No specific FAS/FAE diagnosis is required, and strategies focus on behaviour modification regardless of the underlying cause.

Handicapped Children's Services provides funding for aides, medications, counseling to maintain the child in the home, and limited travel subsidies, although not for assessment and diagnosis, to children with a variety of conditions, including a confirmed medical diagnosis of FAS/FAE. Only a parent or legal guardian can apply for services provided by this organization, which severely limits the services for foster parents. They also provide post-adoption support and counseling to families, including those adopting a child with FAS/FAE. Handicapped Children's Services provides respite services for children on their caseload, including children diagnosed with FAS/FAE. No other formal respite program for families living with a child with FAS/FAE are available.

Several private agencies also offer counseling services in Fort McMurray. There are two psychologists in private practice in Fort McMurray. Also an additional agency, Personal Support Network, offers brief intervention as part of the Employee Assistance Program (EAP) for Suncor, a major employer in Fort McMurray. These agencies do not offer services specific to FAS/FAE, but may provide services to families with a child diagnosed with FAS/FAE related to other psycho-social and family concerns.

There is no formal support group for caregivers of children with FAS. There is an informal network of support between adoptive families and those providing foster care to children with FAS. Respondents were unable to identify even one child diagnosed with FAS who was living with a biological parent. All were either in foster care or had been adopted.

There are no FAS-specific programs in the schools. As noted above , in Section 4.1.3, FAS/FAE is not a diagnosis that is funded under the Program Unit Funding (PUF) grants for special needs.

The Children's Centre, through Early Intervention funding, now has a .5 FTE Mentor working in the schools in Fort McMurray. The focus of this position is not specific to FAS. The Mentor provides anger management training, conflict resolution skill building in children, acts as a buddy to socially isolated children, supervises recreational activities before and after school. For pre-school children referred to the mentor, he would provide activities such as reading to the child, playing ball, or working with the computer with the child, in a 1 to 1 setting for approximately one hour per week.

All respondents identified the need for more expert professionals who could deliver FAS-specific programming and training in the community and specifically within the schools. They also identified the need to address the Alberta Education ministry funding criteria related to FAS diagnoses.

People
All respondents indicated that they had only a basic knowledge of FAS and would not consider themselves as resources to others. When asked to identify experts in their community, no people could be identified.

Resources
Each agency or organization identified that they had small numbers (under 5) of articles or pamphlets related to FAS that they distributed to people as they were requested. Some respondents reported that they are now using the Internet to gather information. There has also been no local organized media attention given to FAS. Provincial or national advertising campaigns seen on television are the only media that the community has seen related to FAS. Posters in health facilities and school health classes are the only other incidences of FAS awareness that respondents could identify.

Respondents identified the need for a localized and publicized resource library of both print and multimedia . Collecting the resources of individual agencies, enlarging the holdings and housing the collection in an organized and accessible manner was identified as a local need.

5.1.6 Knowledge and Source of Knowledge re: FAS

Children's Centre staff state that they have a beginning understanding of FAS/FAE, but require more in-depth information on specific intervention strategies. One of the Centre's staff completed the "Challenged Children" course and shared the limited information related to FAS/FAE with the remainder of the staff. Staff members have attended local workshops in the past. Three staff attended a recent FAS conference in Maple Ridge, BC, as part of this project. The Children's Centre staff identified the information gained at the conference as invaluable in enlarging their understanding of the implications and concrete strategies to work with children diagnosed with FAS/FAE. The conference provided an excellent opportunity for several staff from each location to gain a common level of understanding of FAS/FAE and to build resource contacts for future training.

Other agencies and organizations stated that knowledge levels in their organizations varied by person. However, no one felt that they had more than a basic knowledge of FAS. Schools and medical professionals were seen as having very limited knowledge of FAS.

AADAC has sponsored several half-day workshops related to FAS/FAE, for health and social services professionals over the years. In 1997, AADAC in partnership with the Northern Lights Health Region presented a 1 day conference on FAS/FAE: " Living in the Shadows". This conference was aimed at professionals and had an attendance of 87 people.

Foster and adoptive parents identified that they often had more information and understanding than the social services and medical professionals who were supposed to be assisting them. These parents identified out of town physicians, and the Internet as the primary sources for their information.

The knowledge levels of the community are reported by all respondents as minimal. As stated above, no formal public awareness campaign has been mounted in Fort McMurray. The "Don't drink if you're pregnant" prevention message is taught in health classes, displayed on posters in clinics and periodically seen in advertisements on television. However, key informants felt that unless personally impacted, this message has largely not been internalized by community members.

All respondents identified the need for coordinated, ongoing education and training for both the general public, caregivers, and professionals.

5.1.7 History of Community Collaboration

All respondents noted that in an isolated community such as Fort McMurray, agencies had to work together. There is a long and strong history of collaboration on a variety of community issues. All the agencies and organizations were aware of each others' programs and services and had worked together previously on various committees and issues. In the same way, there was an established cross-referral pattern between all agencies. The Children's Centre was identified as a key player in the community. It was noted they are always "players at the table". This is a real strength of The Children's Centre program and a necessary requisite for FAS/FAE coordination and collaboration.

Prior to the inception of Health Canada FAS funding initiative, in November, 1997 AADAC, as part of a provincial initiative, called a meeting to develop a way to address FAS in Fort McMurray. The result of that meeting was the development of the Northern Lights Regional Working Committee on Fetal Alcohol Syndrome. Committee members represent the following organizations: Parent Child Resources, Northern Lights Regional Health Centre; St. Paul's School; Office of the Commissioner of Services for Children/Families; START program, Salvation Army; Fort McMurray Association for Community Living; Fort McMurray Public School District; Alberta Family and Social Services; Family Service Agency, Municipality of Wood Buffalo; AADAC; Anzac School; The Children's Centre; and Keyano College. It is of interest to note that the medical community is not represented on this committee. At their inaugural meeting, committee members had brainstormed possible issues, strategies and needs for their community and region, but had not finalized any plans.

The Northern Lights Regional Working Committee on FAS was already in place when the Children's Centre was approached about being a pilot site. The Children's Centre was able to bring funding from this pilot to the Working Committee. The Working Committee made decisions about how the project would unfold. The pre-existence of the committee allowed for a timely start to this pilot, with objectives and plans that had already been discussed at least in a preliminary way. One respondent noted " This is not just a spur of the moment response to funding, but comes from a history of working together, knowing the previous needs and requests and being able to make a clear plan. We can all see how working together works best.". Another respondent stated that " It was so nice that the Children's Centre could bring this to the table for all the committee to work on together. A strong sense of community collaboration was found in all responses. All members of the working committee interviewed spoke of the project as "our FAS project" not the Children's Centre project.

5.1.8 Gaps/Barriers in FAS Services and Programs

Respondents identified several gaps and barriers in effective FAS services and programs in Fort McMurray. The first was a lack of locally available diagnosis and thereby development of treatment plans. Training of local pediatricians was identified as a need.

Ongoing training of health, social services and school professionals was identified as a large need. The coordination and development of expanded print and multimedia resources, including resources in Aboriginal languages, was also identified as a community need by all respondents. Public awareness through targeted, appropriate messages and mediums was also identified as key in primary prevention. It was also reported that a lack of formal linkages and support between adoptive/foster parents and social services professionals leads inadequate and fragmented services.

5.1.9 Summary of Baseline Data for Fort McMurray Children's Centre

In summary, Fort McMurray can be characterized as a community rich in collaboration and poor in resources. All agencies and organizations are working together, beyond capacity, to meet the needs of children with FAS in their communities. The lack of specific services or programs directed at children and families living with FAS/FAE means that individual agencies are responding in an ad hoc manner.

Staff at The Children's Centre and members of the Working Committee are sophisticated professionals comfortable with program development and inter-agency collaboration. However, all are already working to capacity in their organizations to meet existing mandates, without the addition of FAS/FAE programming or services.

There was a strong consensus from all respondents that having diagnostic services available in Fort McMurray would be highly desirable and would positively affect the lives of many children currently not diagnosed

All respondents also identified the need for more expert professionals who could deliver FAS/FAE-specific programming and training in the community. All respondents identified the need for coordinated, ongoing education and training for both the general public, caregivers, and professionals.

Training targeted to schools was identified as a key need. Respondents also identified the need to address the Alberta Education ministry funding criteria related to FAS/FAE diagnoses.

Respondents identified the need for a localized and publicized resource library of both print and multimedia . Collecting the resources of individual agencies, enlarging the holdings and housing the collection in an organized and accessible manner was identified as a local need.

5.2 Lethbridge Native Women's Transition Home

Lethbridge is a city of approximately 65,000 people. There are an additional 8,000 people on the adjacent Blood Reserve.

5.2.1 Current Programs

The Lethbridge Native Women's Transition Home (LNWTH) began in 1994 to provide a residential program for women and their children who are leaving abusive relationships, moving to Lethbridge or are transient. The program can house 8 families. They also reserve 2 units for emergency needs. Additionally, they offer a Head Start program for 3-5 year old Aboriginal children who reside within the Lethbridge city limits. There are 15 children ages 4 and 5 in each of a morning and afternoon class run 4 days per week. There is also a class of ten 3 year olds who meet from 1030 to 1430. The mandate of the Head Start program is to provide a culturally appropriate program for primarily, high risk Native children in Lethbridge. Children are from families experiencing one or more of the following situations: receiving social assistance; single parent; families involved with Child Welfare; alcohol/drug abuse issues; homelessness or family breakdown.

The Home/Head Start program is staffed by six full-time and three part-time employees. Funding comes from three different sources.

5.2.2 FAS in Context

Of the 40 children in the Head Start program, no child has been formally diagnosed with FAS/FAE. Staff identified 3-4 children suspected of having FAS/FAE. Three of these children are living with their biological mother. Staff had not previously considered the incidence of FAS/FAE among the women in the transition home, but felt that this could be an influencing factor in several of the families that had been residents of the Home , both past and present.

Lethbridge Family Care is a private agency that provides foster care placements, among other services. They currently have 10 children diagnosed with FAS placed with their care providers. There are also three young adults with FAS/FAE in a group home under the auspices of Lethbridge Family Services.

Again, as in Fort McMurray, there is great difficulty in determining an incidence rate of FAS/FAE in the Lethbridge community. Individual agencies do not have readily accessible data about the numbers of children diagnosed with FAS/FAE who receive their services. Other than Handicapped Children's Services, no agency requires a diagnosis of FAS/FAE to provide services to a child. Because Lethbridge is a larger city, it was even more difficult for professionals to "guesstimate" FAS incidence.

Some incidence data comes from a 1996 study of children in ECS to grade 3 on the Blood reserve. Of 400 children assessed, 20 had official diagnoses of FAS/FAE. An additional 120 were identified as requiring further assessment related to FAS (Pace, 1997).

5.2.3 Current Diagnostic Process

Diagnosis of FAS is also a concern in Lethbridge, although for reasons that are different than Fort McMurray. There are two pediatricians in Lethbridge who will diagnose FAS. However, they are reported to be reluctant to take any more cases on because of the time and legwork needed to make a diagnosis. One of the pediatricians, and a developmental neuro-psychologist are currently spearheading an initiative in Lethbridge to develop some type of diagnostic team. The concept is based on a similar team approach used at the Bear River program in Logan, Utah. They have identified advantages to such an approach: each member knows their role, and other members know what each other is doing; because each professional knows their role in the process, a diagnosis can be achieved much quicker as there is coordination and no duplication; and the follow-up is better again because of coordination of roles and responsibilities.

A teacher, parent (biological or foster), or social services personnel trigger the current diagnostic process. There are then two routes to a referral to a pediatrician for a definitive diagnosis. The child may see a family physician who determines whether or nor to refer to the pediatrician. (This was noted as a problem in Lethbridge, because of the level of knowledge of FAS among family physicians.) If a referral is done to a pediatrician, the pediatrician then refers the child out to a psychologist. The other route involves an initial referral to a psychologist, who after completion of a psychological assessment, refers directly to the pediatrician. However the child comes to be referred to the psychologist, the child is assessed for approximately 6 hours over a week. Assessment includes a cognitive battery of tests and a neurological assessment. Additionally, the psychologist collects a behavioural assessment from the parent and teacher, and completes one with the child. The teacher also completes a social behaviour checklist. An intensive interview is conducted with the biological mother or foster parent and social worker, if no biological mother is available. The psychologist then complies the findings and forwards them along with a suggested treatment plan to the pediatrician. The pediatrician then completes a physical examination and makes the diagnosis.

The following flow chart illustrates these two assessment approaches.

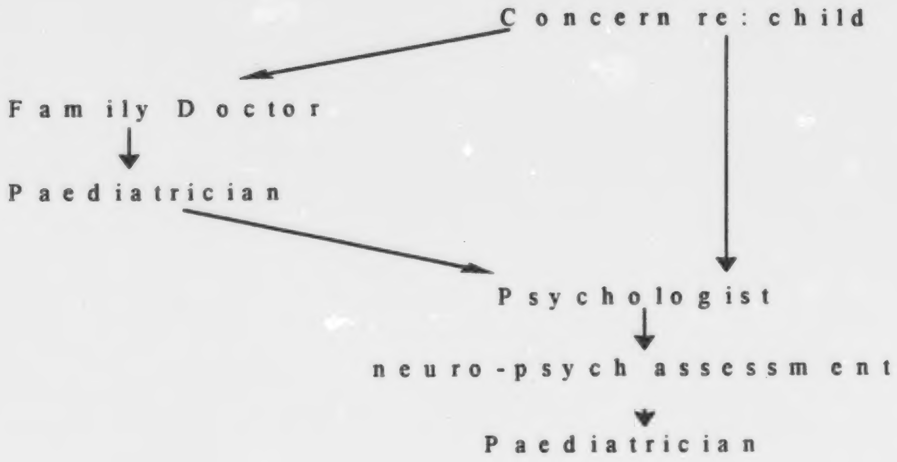


Figure 5.2.3. Flow chart of diagnostic process

Another factor complicating this procedure is the cooperation needed from the child and parent to complete this process. Respondents estimated that children living with their biological mother fail to appear approximately 50% of the time, for either portions of the testing or the pediatrician's visit. Until recently, there has not been a developmental psychologist available in Lethbridge. This meant that in the past, the physician or pediatrician had to coordinate with various social services agencies to fly in the psychologist to complete the necessary assessments. Several agencies were unaware of the arrival of Dr. Pace, the psychologist and were still making arrangements with an out-of-town psychologist. Another problem with this process is that the medical portion of the diagnostic process is covered by Medicare. The psychologist's assessment is not. Therefore, funding for the psychological portion of the assessment is often a deterrent to completing the diagnostic process. As was noted in Fort McMurray, Alberta Family & Social Services also does not pay for assessments. Aboriginal children are eligible for funding of the assessment through Medical Services Branch..

There is also a question in the minds of many Lethbridge respondents about the utility of a diagnosis. There are no funding programs available to provide 1:1 aides in the schools as children with FAS are not eligible. There does not seem to be an advantage of an FAS diagnosis vs ADHD. ADHD is an eligible diagnosis and so more services are available to the child with this diagnosis versus FAS. Several respondents noted that many children with undiagnosed FAS were diagnosed ADHD and put on Ritalin. The Ritalin was seen as more a sedative rather than providing any long-term assistance with behaviour. While the psychologist provides a treatment plan with the psychological and neurological findings to the pediatrician, it was reported that often that plan was not communicated to parents, teachers and social workers. These people then state that a diagnosis is useless because they get no follow-up or plan of action. Communication and collaboration around diagnosis was clearly identified by respondents is a worthy project for the community to be working through.

5.2.4 Current FAS-specific Programming at Lethbridge Native Women's Transition Home

There is no FAS-specific programming in the Head Start program or in the Transition Home at present. Staff identified the need for training in specific strategies for children and mothers with FAS.

Staff members are trained to complete DISC assessments. These assessments are conducted over the summer on children who will be entering the Head Start program in the fall. Staff are reluctant to communicate any finding which would suggest the need for a more in-depth assessment as they fear that the parent would simply remove the child from the program. Staff also suggested that opinions about a child's needs are often better received from a non-Aboriginal "expert". Suggestions were made by staff members about contracting some assessment assistance from the regional health authority's Children's Services division and also working with Dr. Pace on an assessment and referral process. It was also suggested by staff members that bringing services to the Head Start and Transition Home site would be a more viable alternative than simply referring the child to an unknown outside agency. It was noted that parents, especially biological parents, need a lot of support and education related to all developmental and behavioural concerns, not just FAS. Several respondents noted that the parent only has to have one door slammed on them and they are unwilling to try again.

5.2.5 Current Community FAS Programming, Services and Resources

Programs/Services

AADAC provides a variety of services for children and families affected by FAS, while in Fort McMurray the AADAC focus is on education and family counseling related to responsible drinking behaviour.. Professionals knowledgeable in FAS provide counseling services to individuals and families. AADAC also has a variety of resources available, primarily for professionals, that are housed in the library at the University of Lethbridge. They also provide residential, detoxification and out-patient services to pregnant women with alcohol or drug issues. Prevention is seen as AADAC's primary focus.

Working with a provincial committee, the Lethbridge AADAC office is involved in developing 30 second public service announcements, which are presently with an editor, and the translation of prevention posters into aboriginal languages. These will be made available throughout the province and so will also benefit the Fort McMurray project.

Chinook Health Region Children's Services provides physiotherapy(PT), occupational therapy(OT), speech, audiology and language services and pre-school development assessment and counseling to children and families in the region. No diagnosis is required. Children and families can be referred by teachers, social workers or physicians or can self-refer. An Intake Coordinator assesses the need and determines the type of involvement their services can have in each case. Early Intervention teams service various areas of Lethbridge to identify children with developmental and other difficulties as early as possible. For children with FAS, diagnosed or not, PT and OT screening as early as 4 months can lead to management plans with the goal of developing specific neuromuscular groups before problems occur.

Lethbridge Family Services provides counseling and support programs for people with a variety of developmental disabilities and brain injuries. A primary concern for this agency is that they expect to have their clients for the remainder of their lives. The concern for life planning is paramount, especially when there are few places for these clients. A group home for 3 older adolescents with FAS requiring 24 hour supervision is currently funded by the Alberta Government ($200,000/year) and administered by Lethbridge Family Services. The expense of providing a lifelong continuum of care and services is seen as a major challenge requiring the coordination and collaboration of a variety of players.

Lethbridge Family Care is a private agency that, along with other home-care related service, provides foster care for children, many with FAS. This agency is supposed to provide 10 placements, but are presently stretched to 12 because of community need. Previously, they provided respite to other foster parents, but are now only able to relieve their own foster parents. Clients come to this agency from social workers through a central placement committee.

Handicapped Children's Services, as in Fort McMurray, assists with costs arising from caring for a child with a disability. In order to qualify for funding however, the child must have a confirmed diagnosis and a legal guardian must apply for the funding. As noted earlier, costs of assessments are not covered.

The Family Centre provides services in the areas of information, education, support and counseling to children and families not specific to FAS. They are the site of a large lending library of FAS-specific information. The FAS library is supported by funds from the Lethbridge FAS Coordinating Committee, which is described more fully in Section 5.2.7.

An active family support group in Lethbridge provides support, understanding and education to families dealing with drug and alcohol related birth defects. The support group is identified by professionals as the driver behind much of the training and resourcing activities in Lethbridge. The support group offers referral, residential planning and housing information, vocational employment settings, parental support teams and education of the educator (law enforcement, government officials, public). This support group is well connected to provincial, national and international FAS support groups and organizations and has access to the most up-to-date literature and resources. One of the concerns expressed was that although the group is a very strong support it attracts only foster or adoptive parents, and very few Aboriginal parents or caregivers.

Alberta Mental Health has no specific programming related to FAS in its Lethbridge office.

As in Fort McMurray, Lethbridge schools are represented on the FAS Coordinating Committee and so are aware of local initiatives. Programming specific to FAS varies with the expertise of various schools and teachers. It is the perception of several respondents that all aboriginal children are placed in resource or special needs classes when they enter the school system. Some placements may be related to "English as a second language" (ESL) issues, but some are seen as unnecessary by respondents and done without the benefit of assessment. The Lethbridge Native Women's Transition Home Head Start staff have been working with the school system in order to provide supports and direction for students from their program entering the system. Both pilot site staff and social services respondents stated that school personnel are better equipped to manage the behavioural issues related to ADHD than specifically FAS. As was noted previously, a diagnosis of FAS does not qualify the child for funding of an aide or special programming. On the reserve, education enhancement funding is available for children diagnosed with FAS through designated Band funds. There has also been some effort given to including information related to FAS in the CALM program for junior and senior high school students.

People

Lethbridge has several recognized experts in the area of FAS. Dr. L. Storoz, a pediatrician, provides diagnosis, some treatment and referrals for children with FAS. Dr. Storoz is presently leading an initiative to develop a web-site and a consistent diagnostic approach. Dr. D. Pace is developmental psychologist and a member of the Blood tribe. Dr. Pace provides the cognitive, behavioural, and neurological assessments required in the diagnostic process. Dr. Pace is working with Dr. Storoz in the development of a consistent diagnostic approach. Donna Debolt is a nationally recognized expert on FAS. Ms Debolt is a trainer and consultant for Alberta Family and Social Service. Ms Debolt has provided many training workshops for individual agencies and the professional community at large.

Resources

Two library holdings in Lethbridge have been previously noted. AADAC has a large collection related to FAS that is housed at the University of Lethbridge. This collection is aimed primarily at professionals. The second large library of FAS information is housed at the Family Centre. This collection is aimed at the public and is a lending library.

Although AADAC is working provincially on the development of PSA's and the translation of prevention posters, media exposure of the Lethbridge population to information related to FAS has been the result of television commercials from outside organizations. Posters related to prevention can be found in schools and health clinics. No concerted social marketing campaign has been conducted in Lethbridge. Coverage of previous conferences in the local press has resulted in some awareness. However, respondents agreed that unless they have a reason to know about FAS, most of the public is unaware of the term and the implications of the syndrome.

5.2.6 Knowledge and Source of Knowledge re: FAS

Staff of both the Head Start and Transition Home stated that they have a very basic understanding of FAS. Head Start workers have taken the ECS (early Childhood Services) teacher training program. Staff have attended several workshops held locally and several staff have attended a conference in British Columbia as part of this project.. Staff identified the need for specific information related to FAS screening and management strategies, particularly for the classroom and to pass on to mothers.

Foster and adoptive parents, who are not new, have an extensive knowledge of FAS. Through the work of the support group, they have access to the latest information. They have attended conferences and are expert users of the Internet. Pilot site staff and social services respondents reported that biological parents are generally at the other end of the continuum, with little understanding of FAS and its implications for their children. In many instances, the parents of children with FAS are unable to comprehend the magnitude of the diagnosis and implications because they too have some degree of FAS. Educating biological parents is seen as one of the greatest challenges in dealing with children diagnosed with FAS.

The professional community in Lethbridge considers itself to be well informed about FAS. They are also individually able to identify areas where they would like to have more knowledge or skills. There has been ongoing workshops and training sessions within organization and agencies and in the community at large. A conference related to FAS, featuring Dr. Ann Streissguth, held in 1993 attracted 750 people. Individuals in the professional community have attended a variety of provincial, and national conferences and workshops related to FAS.

As noted above, public awareness concerning FAS is limited. The "Don't drink if you're pregnant" messages can be seen on television, posters and in health classes. All respondents identified public awareness as an issue, with the need to target messages to particular age groups and cultural entities.

5.2.7 History of Community Collaboration

There is a long history of collaboration of professional and agencies related to FAS. The FAS Coordinating Committee was established in 1991. This committee planned and hosted a large conference in 1993. They have also produced 3 videos and developed a poster. This committee also funded the development and ongoing maintenance of the FAS library housed at the Family Centre. The Lethbridge Native Women's Transition Home staff were not part of this committee nor were they aware of the committee and its work, although they were aware of the 1993 conference. They were also not aware of the FAS Library at the Family Centre.

A recent committee organized by Dr. Storoz to develop a web-site and to consider coordinating the diagnosis process did invite representation from the Lethbridge Native Women's Transition Home, however, they were unable to attend.

Social Services and health care agencies have worked together on a variety of issues. However, the Lethbridge Native Women's Transition Home has not been involved with the larger professional community.

There was a lack of understanding of the work of the Transition Home by several members of the professional community who had not heard of it or had need to use its services. AADAC identified that they had several common clients with the Transition Home in the past, but that AADAC's confidentiality requirements made case conferencing and collaboration difficult. Children's Services at the regional health authority had visited the Transition Home once in the past. They had not referred or had referrals from the Transition Home in the 6 months since the visit. Handicapped Children's Services has worked with the Head Start program in the past. Within the Aboriginal community itself, knowledge of the Transition Home was also limited. The staff of the Transition Home and Head Start were also not well acquainted with the services available in the community. Several explanations were given for this. As earlier noted, staff are reluctant to refer for fear that parents will simply remove their children from the program and be lost to any intervention. Secondly, some contacts that may have existed in the past may have been lost in the restructuring and reorganization of the health and social services systems. Finally, it was suggested that it would be natural for the Transition Home to isolate themselves from systems that have not been seen as supportive to them, as individuals and as a group, in the past.

5.2.8 Gaps/Barriers in FAS Services and Programs

Respondents identified the need for a coordinated and streamlined diagnostic process. Another strong concern was the need for coordinated management or treatment planning, so that services don't just stop with diagnosis. Because of the availability of services in Lethbridge, many of the concerns were more related to primary prevention and lifelong planning and resourcing for people living with FAS/FAE..

5.2.9 Summary of Baseline Data for Lethbridge Native Women's Transition Home

In summary, Lethbridge is an area rich in resources related to FAS and with a long and strong history of community collaboration. In the midst of these riches, the Lethbridge Native Women's Transition Home sits like an island. Their attempts to reach out to the larger community of service providers has been met with encouragement, but with some confusion about what is being asked of the larger community.

6 Development of Pilot Projects

Two CAPC sites were selected, according to criteria outlined in Section 1.4, to implement secondary prevention efforts that target women before and during their childbearing years and tertiary prevention efforts that target children suspected of or diagnosed with FAS/FAE. Site selection was finalized in November 1997. Projects were to be completed by April 1998. A consulting team provided site-specific consultation in program and resource selection and adaptation, staff training and program implementation.

The Children's Centre in Fort McMurray was given a budget of $ 25,000.00. Their project plan included (See Appendix E for Fort McMurray Project Material):

- Attendance at the Maple Ridge Workshop;
- Development of an FAS/FAE Resource Library;
- High School Drama Production;
- Impact Radio Advertising;
- Poster Contest; and
- Present "Families, Communities & Fetal Alcohol Syndrome Conference in Fort McMurray.

The Lethbridge Native Women's Transition Home received funding of $23,800.00. Their project was the development of a protocol (process) for accessing assessment and support services related to FAS/FAE for children in their Head Start Program (See Appendix F).

6.1 Fort McMurray Children's Centre

The Children's Centre is a member of the Northern Lights Regional Working Committee on FAS/FAE. This Working Committee had been established as part of a province-wide initiative prior to the beginning of the Health Canada FAS Project. The Working Committee had established a list of priorities and proposed projects at their initial meeting in December, 1997. The committee had not outlined a specific mandate, but had only brainstormed ideas.

In mid-December Liz McDougall, Carol Oliver, and Heather White visited Fort McMurray to meet with the Pilot Site and clarify the project. When The Children's Centre was selected as a Pilot Site, its staff returned to the Working Committee with the financial resources, and the Working Committee became involved, as an ad hoc steering committee, in identifying activities to be undertaken as part of the Pilot Project. The Working Committee is comprised of 14 people representing various social services, health care and education agencies/organizations. The committee met four times over three months to organize and carry out the pilot project. The Children's Centre, in conjunction with the Northern Lights Regional Working Committee on FAS/FAE completed the following activities that brought the issues of FAS/FAE to the attention of their community.

6.1.1 FAS Workshop in Maple Ridge

Three employees from The Children's Centre attended the Fetal Alcohol Syndrome Workshop in Maple Ridge B.C. in January, 1998. This workshop assisted in giving them a framework and contacts for their own conference and provided them with a good beginning understanding of FAS/FAE.

6.1.2 FAS/FAE Resource Library

The Children's Centre contracted with an individual to develop a solid and usable resource library related to FAS/FAE. This person planned, researched, purchased and catalogued a library specific to FAS/FAE. The Resource Library opened on May 1, 1998, in the Provincial Building on the 9th floor. The actual space is provided by C.H.O.I.C.E.S., a non-profit employment agency that has participated in the FAS/FAE initiative. There is a sign-out protocol, a reading area with chairs and tables and access to photocopying. The resource library will available to the public and professionals. Advertising of this resource is found in the Community Calendar section of the local newspaper and on the local TV scanner. The Children's Centre and the Working Committee will continue to advertise the existence of these materials.

The resources provided by the project will be kept within The Children's Centre. Many of the materials are also available in the C.H.O.I.C.ES. library. Keeping the resource material at The Children's Centre will allow staff immediate access to this information.

6.1.3 Community Engagement and Awareness

It was determined that the best way to engage the target group of early to late adolescents selected by the Working Committee, would be to find ways for them to directly participate in the initiative. A second person was contracted to coordinate, organize and complete activities with this target group. Three specific activities were developed.

Drama project: the Westwood High School drama group scripted and presented an improvisational type of production related to FAS and drinking during pregnancy. This production was presented to other schools throughout the spring. A number of foster parents and community workers knowledgeable in FAS/FAE agreed to attend these productions to answer questions and provide information on the issue. The production is also being videotaped by a local television station.

Impact Radio Advertising: The High School Drama group also created 30 second radio spots designed to initiate conversation about FAS/FAE and targeted to the adolescent age group. These are being run on a local radio station and on the Aboriginal station originating in Edmonton. The local radio station has run the radio spot twice every evening for the month of April. Because the project was funded, the radio spot was eligible to be a public service announcement, but had to be paid advertising.

Poster Contest: A poster contest was held for junior and senior high school students. Presentations on FAS/FAE and drinking during pregnancy were given in the health classes to provide the basic understanding needed for the contest. Fifty-six (56) entries were received. First, second and third prizes were awarded. Winning posters are being reproduced and will be distributed to community agencies and physicians offices in Fort McMurray and to clinics in outlying areas during May, 1998.

6.1.4 Families, Communities & Fetal Alcohol Syndrome Conference:

A free one-day conference was held on March 21, 1998, with 146 people attending. Providing the conference free of charge allowed many non-professionals, including caregivers and parents to attend the conference. Mary Vandenbrink, a provincial trainer from Edmonton, was the main speaker. A resource panel of local individuals working with clients and families around FAS issues was also included in the program. The panel included an adoptive mother of two FAS children. Social worker, youth worker, and leading trainer and advocate on FAS/FAE from Edmonton. Attendees included birth, foster and adoptive parents of children diagnosed with FAS/FAE, community professionals in the areas of education, health and social services, and college students. A sign up opportunity was provided for those interested in a support group. Seven people, including 4 foster parents and 3 adoptive parents indicated their interest in a support group. Plans are in place for the group to commence meeting in September, 1998.

6.2 Lethbridge Native Women's Transition Home

A local coordinator was hired on a contract basis to provide the leadership for this pilot project. Two community meetings in December, 1997 and a third meeting with local social services providers in January, 1998 served to connect the Pilot Site to other community resources and initiatives related to FAS/FAE and provide awareness of the Pilot Site's project to the larger community. It was determined that the best approach for this site would be the development of a protocol (process) for accessing assessment and support services related to FAS/FAE for children in the Head Start Program. This process includes screening with the DISC tool that is completed by the Head Start teachers. The assessment and support protocol is being developed in collaboration with Dr. L. Storoz, a local pediatrician, and Dr. D. Pace, a local Aboriginal neuropsychologist. Once the protocol is finalized, three children will be piloted through the process to validate and adjust the process.

7 Evaluation Findings

Evaluation findings are structured around answering the following questions:

- What worked?
- What would you do differently?
- What difference did it make that you did this work? And
- What are the next steps?

7.1 Fort McMurray

7.1.1 What worked?

Informants from Fort McMurray indicated that having the Working Committee already functioning was a major reason that they were able to accomplish so much in a short time period. They did not have to take much of the available time for planning as it had already been done.

The workshop in Maple Ridge was also reported to have provided a kick-start to the project by quickly getting three of The Children's Centre staff up to speed on the current thinking around FAS/FAE diagnosis and programming. Having a group of people who had heard the same information was seen as useful for providing a shared understanding of the issues and strategies which could then be shared with others.

Contracting out the task of assembling the resource library was the only way that staff from The Children's Centre stated they could have accomplished this. The collaboration of other members of the Working Committee in providing space for the resource library was also positive in that the venue will be much more accessible to the target group than The Children's Centre would have been.

Working with high school students to produce various media was seen by all as a positive and successful strategy. Students and teachers viewed this collaboration as positive. The development of a variety of posters was also seen as a success. Various communities prefer different posters and so the posters selected by each community are specific to their particular community needs.

The conference was seen as a success by both the organizers and the participants. Fifty-eight of the participants returned a participant evaluation form that was coded and analysed. The majority of these respondents indicated that they wanted two things from the conference: general knowledge about FAS/FAE and practical strategies for working with children, adolescents and families affected by FASE/FAE. In open ended comments, respondents indicated that they had received basic information but would like additional information specific to their areas of interest, such as education or behaviour management. Respondents had learned of the conference primarily through their worksite (21%), The Children's Centre (16%), Keyano College (14%), Schools (8%), flyers (8%), and newspaper (7%). Other sources noted by a small number of respondents included

Salvation Start, poster, TV, Working Committee, Foster Parent Association and word of mouth. Responses to additional questions related to next steps to be taken are found in Section 7.1.4).

Organizers were pleased that a large cross-section of people attended the conference, however, they were also discouraged that no medical professionals were in attendance, despite having been specifically invited. The number of people attending the conference exceeded the original expectations of the organizers by approximately thirty people. Organizers felt that the presentation offered a strong beginning understanding of FAS/FAE as over half of the participants indicated that they had never heard about FAS/FAE before. Participants and organizers both commented that having a speaker with a personal understanding of FAS/FAE, rather that just a professional perspective greatly enhanced the speaker's credibility.

7.1.2 What would you do differently?

Time and timing were noted as problem areas. Respondents in Fort McMurray suggested a minimum one year and preferably two year project. Stable funding for that period of time would enable sites to spread the work over the time frame, taking into account items such as year end and vacations. Because of the decisions made about programming and the resulting budget, no money was available for release time for the Executive Director or Program Coordinator at The Children's Centre. The people in these two positions felt that it was a good thing that the time was limited in this case, because they would not be able to keep up the workload required to maintain ongoing programs and develop the FAS initiative. They noted that in the future, they would hire a coordinator for such an initiative. Although they did hire two contractors to work on the resource library and school -related projects, they were left with many of the administrative details, such as negotiating for space for the library, negotiating prices for the radio spots and completing the variety of tasks required in overseeing the planning and implementation of the conference.

The Children's Centre had initially identified training for their pre-school teachers as a need. Administrative staff at The Children's Centre stated that program staff required basic knowledge before specific training would have been helpful. Now that staff have attended the Maple Ridge, BC Workshop and the local conference, additional more specific training needs can be identified. Teachers would like to have some training, implement the strategies and then come together for further training and to evaluate the implemented strategies after 6 to 12 months.

The Children's Centre staff noted that because of the well-developed Working Committee, they did not require the assistance of an outside project consultant in the way that other pilot sites might. They also suggested that contact with both Health Canada and the Project Consultants was redundant at times, with both calling and the same materials having to be faxed independently to both.

7.1.3 What difference did it make that you did this work?

Increased community awareness was the first answer given by all informants. School students involved in the poster contest and the drama group had presentations about FAS/FAE and using alcohol during pregnancy prior to completing their projects. This would not have occurred without this initiative. All junior and senior high school students within Fort McMurray will also see the drama produced by the high school students.

There is also a heightened awareness among the caregiver and social services sector as a result of the conference. Radio spots and the newspaper advertising of the conference provided a vehicle to at least introduce FAS/FAE to the general public in Fort McMurray.

Members of the Working Committee have begun to work together to initiate programming related to FAS/FAE in this pilot. They have grown in their awareness of the implications of FAS/FAE for a variety of provider groups, caregivers, and children. This awareness has led to their concern that newly announced provincial funding will be directed mostly toward primary prevention with the lifelong needs of children currently living with FAS/FAE being ignored.

7.1.4 What are the next steps?

All participants in focus groups and key informant interviews were asked what they felt were the next steps to be taken in Fort McMurray regarding FAS/FAE. Conference participant evaluation forms also asked the same question. Five specific next steps were identified that could be addressed with Fort McMurray. An additional more global theme was also identified.

1. Sustain current initiatives: Respondents identified the need to continue funding to maintain the currency of the resource library and to encourage the development of partnerships to provide this in the long term. Drama students have not been able to deliver their presentation to junior high school students in outlying communities because of travel costs. Additional funding would enable this initiative to be expanded.
2. Facilitate the development of a Support Group: Many respondents identified the need for a support group led by an experienced facilitator. It was noted that without an experienced and knowledgeable facilitator, there is no one to provide direction and insight to the group. A support group without some professional input was seen as at risk of becoming only a place for complaining rather than for gaining insight and support.
3. Increase Skill Development: Ongoing workshops were requested by all categories of respondents. A planned, continuing series of workshops targeted to specific audiences was suggested as a way to begin to build skills among a variety of people including parents and professionals. The Children's Centre staff would benefit from an ongoing educational program that would present information, allow staff to try the strategies and then come back to the same trainer to evaluate and refine their strategies. This same type of skill building was also requested for school teachers.

Workshops targeted to parents, family visitors, including health and social services staff, and law enforcement staff were also suggested. No physicians attended the Conference. It was identified that workshops on FAS/FAE provided by physicians for local physicians are essential to provide a level of consistent information about assessment and ongoing management of children diagnosed with FAS/FAE. Physicians are seen as key players in providing support to children and families living with FAS/FAE, but only when their knowledge and skill are current.

4. Target primary prevention strategies: Many respondents identified the need to target primary prevention messages to teens through the school system. All students in grades 9-12 from the outlying communities must board in Fort McMurray to attend school. School is then the primary venue to reach this age group. One respondent commented " If they don't learn about FAS in school, where would they learn about it?". There are no fool-proof ways of getting the prevention message to this high risk group, and so opportunity must be given to try a variety of approaches to identify strategies that work with the teen population in Fort McMurray.

   A second high risk group identified as needing primary prevention information is pregnant women. Opportunity is needed to develop strategies to target pregnant women through pre-natal programs, women's circles, clinics and physician offices. Appropriate information available through visual media, and not only print media is required. Materials in local aboriginal languages would also be useful.

5. Access to early diagnosis and treatment resources: As was noted in Section 4.1, no local diagnosis team is available. Many respondents "dreamed" of a mobile team that would come to Fort McMurray on a regular basis to provide not only diagnosis, but ongoing treatment and management planning for the child, parent and health, education and social services personnel. Diagnosis alone is certainly a necessary step, however on its own, without follow up and treatment planning, it is empty and causes more problems than it solves.

From the collection of baseline data, interviews, focus groups and conference participant evaluations, the greatest need identified is comprehensive, consistent, locally available wrap-around lifelong services for children and families living with FAS/FAE. As individuals talked about their vision for this type of service, it was clear that they were describing what the literature refers to as a family resource model. Skilled and competent professionals are needed to assist in addressing the needs for services identified by respondents. When describing the "dream" service delivery model, respondents included the following:

- Diagnosis by an expert team who would continue to work with the child, family, and community resources to develop behaviour management instructional and treatment plans. If a mobile "virtual" team approach is used, there must be consideration given to strategies to developing trust with "outside" professionals who are not part of the community network.
- Schools with teachers skilled in teaching children diagnosed with FAS/FAE. Adequate funding for trained in-school aides to assist these children;

- Professional resources to assist parents and caregivers in coping with the demands of raising a child affected by FAS/FAE;
- Respite for families of FAS/FAE affected children of all ages, including adolescents and adults;
- Residential and vocational options for adolescents and adults affected by FAS/FAE;
- Advocacy with local, provincial and national governments related to primary prevention, funding for additional educational and support services for children diagnosed with FAS/FAE and legal and justice system issues.
- Support from the two major employers in Fort McMurray, and recognition that their boom and bust cycles have a major impact on the people of Fort McMurray.

7.2 Lethbridge Native Women's Transition Home (NWTH)

7.2.1 What worked?

Although the time was short, the process of allowing the Lethbridge site to work through a variety of ideas and issues before arriving at an action plan was very effective. Forcing an earlier adoption of an action plan without the lengthy consultative and reflective process would not have yielded a plan that addresses the unique needs of the Native Women's Transition Home (NWTH) and their Head Start program.

The three community meetings were identified by all respondents as a very useful strategy for this site. Because, the NWTH is not a member of the Lethbridge FAS Committee, it was not possible to use that committee in the same way as was done in Fort McMurray. Instead, the community meetings served to provide the NWTH staff and pilot project facilitator with an introduction to community programs, services and resources. These meetings also served to inform the larger community of service providers of the needs, issues and programs of the NWTH.

Collaborating with Dr. Pace, a neuropsychologist, and Dr. Storoz, a pediatrician, in the development of a process for screening, assessing and supporting children, was a very successful strategy. Through the process, the pediatrician gained insight into many of the issues and frustrations encountered in dealing with children suspected of having FAS/FAE. The pediatrician was also not aware of the cultural beliefs and values of the local Aboriginal communities, but was eager to learn.

Both the NWTH Director and the pilot project facilitator indicated that having a member of the Consulting Team providing mentorship was a very necessary strategy. The overall guidance and assistance with process development were reported as a useful strategy that allowed the project to make as much progress as it did. These respondents reported that they would not have known what to do or what direction to take without the guidance of the member of the Consulting Team.

7.2.2 What would you do differently?

Both the Director of the NWTH and the pilot project facilitator noted that they had taken almost the entire time of the pilot just to decide what direction to take. This left them with very little time to actually implement their strategy. Therefore , they recommended a longer pilot project of 1-2 years. A longer time frame would allow sites such as Lethbridge, the process time necessary to arrive at a viable action plan, without feeling pressured by time just to do "something, anything" to appear successful.

The timing of the pilot within the school year is also providing some challenges as they seek to pilot the assessment protocol developed. Issues related to parental consent for screening by Head Start teachers, not requested at the beginning of the school year is posing a challenge yet to be addressed. Parents consent to the initial intake screening prior to their child entering the Head Start program. There is no provision in the consent for ongoing screening of the child once the child is in the Head Start program. They may need to wait until the beginning of the next school year to pilot the protocol while the Board of the NWTH reviews their parental consent document and screening/testing policy.

The availability of a local mentor to the project was suggested by the Executive Director of the NWTH and the Consulting Team. Because of the distance involved, only three on-site meetings with the Consulting Team were held. Although there was a great deal of telephone contact, all parties noted the advantages to a locally available mentor.

7.2.3 What difference did it make that you did this work?

Great strides in the awareness and understanding of FAS/FAE within the NWTH and Head Start programs are the major effects of the pilot project to date. Attendance at the Maple Ridge Conference, reading and viewing resource materials and discussion both with the Consulting Team and within the NWTH and Head Start staff have begun to add layers of understanding of the immense nature of the issues related to FAS/FAE as they specifically apply to Aboriginal people.

The connection with the larger community of service providers provides the NWTH with a greater degree of understanding of the services available and comfort in knowing some of the people involved at the various agencies. An increased understanding of the work of the NWTH by the larger community is also a beneficial outcome of this pilot project.

The identification key resource people in the community, specifically Dr.'s Pace and Storoz and the willingness of these people to work with the NWTH should continue to provide positive support to the NWTH in the future. Dr. Pace's personal understanding of and connection with the Aboriginal community, coupled with her professional skills and enthusiasm for working with the NWTH would not have been known had it not been for the community consultation completed as part of the pilot project.

7.2.4 What are the next steps?

The assessment protocol has yet to be finalized, with several meetings scheduled for April, 1998. Once the protocol is finalized, the process must be tested and validated with 1-3 children.

Ongoing training of the staff of both the NWTH and the Head Start is an outstanding need identified in the pilot. Training was also suggested for parents as part of the "Parents as Teachers" component of the Head Start program. All respondents noted the need to nest the FAS/FAE initiative in the broader consideration of assessment and planning of strategies and services for children identified as at risk because of a variety of development and learning delays, not only focused on FAS/FAE.

7.3 Project Management

7.3.1 What worked?

In a very short time frame, a large, comprehensive collection of reviewed resources was acquired, two pilot projects were initiated in diverse CAPC projects, and two feasibility studies were completed. The proposal for this project was developed on the advice of external experts with only a beginning understanding of all the issues, however, the approach worked for the timeframe available.

Initial meetings in each site were useful in providing the Consulting Team with a baseline understanding of not only the programs of each site, but the social, physical and geographic environment in which they were located. The opportunity for face-to-face meetings with a variety of people in each site also served to provide a broader perspective on the individual community and its particular strengths and needs related to FAS/FAE. Assigning one member of the Consulting Team to work with each site subsequent to the initial visits proved to be a valuable strategy to streamline communication between the Team and the pilot sites. The strategy of the Consulting Team to give projects "creative space" and to live the principles outlined in the introduction , allowed projects the dignity to proceed in ways that were congruent with each site's values and ways of working.

The attendance of people from both pilot sites and the Consulting Team at the Maple Ridge Conference provided a valuable reference point . Because of the common understanding, references could be made back to specific speakers or anecdotes as related to issues arising at the pilot sites.

Regularly scheduled meeting with Health Canada were useful to both parties. Health Canada was kept apprised of the state and progress of project and never felt "out of the loop". These timely and efficient meetings also assisted the Consulting Team in refining the focus and conduct of the project.

Using a team approach was a useful strategy. The different perspectives brought by each member of the Consulting team in collaboration with Health Canada yielded a view of FAS/FAE and the pilot projects that would have been difficult to generate with only one person.

7.3.2 What would you do differently?

As noted previously, time and timing were also issues for the Consulting Team. The time needed to identify, gather and review resources was enormous. Because of the timing, this task was not completed until near the end of the project. The result was that the Consulting Team was not able to provide the type of input that they would have like to related to best practices and practical strategies for the pilot sites. The enormity of the task of maintaining current resources should not be underestimated in future program planning.

With the experience gained from this pilot, assessment of future sites would allow for more individualized models of contact for each site. As noted in the pilot, Lethbridge required and requested extensive, "hands-on" mentoring, while Fort McMurray did not identify the need for assistance from the Consulting team. Individualizing the amount of support provided to sites would balance and therefore maximize the use of available resources. A longer project would also allow for relationship building between the sites and the Consulting Team. Once a relationship had been developed, a more collaborative process could occur.

The role of the Advisory Committee in this project was progressively developed throughout the length of the project. Individual members of the committee provided valuable advice and resources to the Principle Consultant throughout the project. The mid-point meeting of the Advisory Committee provided the opportunity for a process check and validation of the assessment and action plan developed. It was noted that although originally proposed, the Advisory Committee meeting did not have representation from the Aboriginal community, caregivers or persons living with FAS/FAE.

7.3.3 What difference did it make that you did this work?

The sudden emergence of FAS/FAE on the provincial agenda was unanticipated. However, the learnings from this project have served to make Health Canada a well-informed player, well-positioned to take leadership on this issue. The collected resources and meetings with Health Canada personnel and the Consulting Team have provided a level of content expertise and process experience with FAS/FAE projects. Information from this project can help guide Health Canada as they consider their role as a partner in the infrastructure needed to address FAS/FAE in a comprehensive manner.

The review of resources, literature and best practices is of great value. Collecting materials without review is risk-intensive. The large investment of time in reviewing materials for this project is an outcome that will benefit CAPC sites and Health Canada for many years.

Four CAPC programs- 2 pilot sites and 2 feasibility sites- have an increased awareness and understanding of FAS/FAE. The two pilot sites have been able to identify needs related to FAS/FAE and take beginning action to address those needs. It must be continually remembered that that role of CAPC project staff is to promote healthy child development, protect children from risks, and provide support to caregivers, often by working day-to-day with children identified with FAS/FAE. While building on the strengths of CAPC projects, planning must consider the limitations, structural, resource and skill, of these projects to be able to deal with the requirements of FAS/FAE programming and services.

7.3.4 What are the next steps?

Future planning must be optimistic about the opportunities, but realistic about the challenges of FAS/FAE. Continued funding for the two pilot sites is essential, not only to enable them to continue this initiative, but also to give Health Canada a venue for exploring a variety of programming and intervention models in known sites. Specific recommendations are given in the following section.

8 FAS/FAE Resources Collected for Pilot Project

The following resources were collected and distributed to the pilot project sites. They serve as a foundation of resources for CAPC programs as they build their internal capacity to address FAS/FAE.

8.1 Books and Documents

Dorris, Michael. *The Broken Cord*. New York, N.Y.: Harper Collins Publishers. 1989.

Kleinfled, Judith, and Siobhan Wescott (eds.) *Fantastic Antone Succeeds! /Experiences in Educating Children with Fetal Alcohol Syndrome*. University Of Alaska Press. 1993.

McCreight, Brenda. *Recognizing and Managing Children with FAS: A Guidebook.* Washington, D.C: CWLA Press. 1997.

Stratton, Kathleen, and Cynthia Howe, and Frederick Battaglia, (eds.) *Fetal Alcohol Syndrome: Diagnosis,* Epidemiology, *Prevention and Treatment*. Washington, D.C.: National Academy Press. 1996.

Streissguth, Ann. *Fetal Alcohol Syndrome: A Guide for Families and Communities.* Baltimore, MD: Paul H. Brookes Publishing Co. 1997.

Streissguth, Ann. *The Enduring Effects of Prenatal Alcohol Exposure on Child Development.* Ann Arbor: MI. The University of Michigan Press. 1993.

Streissguth, Ann, and Barr, Helen, Julia Kogan and Fred Bookstein. *Understanding the* Occurrence *of Secondary Disabilities in Clients with FAS and FAE*. Centers for Disease Control and Prevention. 1996.

8.2 Resource Manuals and Kits

AADAC, (1996). FAS and Other Alcohol-Related Birth Defects (Second Edition)

Bibber, Marilyn (1997). It Takes A Community: A Resource Manual for Community Based Prevention of FAS/FAE

Research Program, School of Social Work, University of Victoria.

Dubienski, Nykola. (1996). Five Booklets of Fetal Alcohol Syndrome/Effects: (1) Identifying FAS/FAE; (2) Parenting Children (0-12 Years) Affected by FAS/E; (3) Parenting Adolescents Affected by FAS/E; (4) Educational Approaches for Children with

FAS/E, and (5) Working with FAS/E Adults. Edited by The Family Support Working Group of the Committee on Alcohol and Pregnancy and the Fetal Alcohol Support Network of Manitoba.

FAS/E Support Network of B.C. (1995). A Layman's Guide to Fetal Alcohol Syndrome and Possible Fetal Alcohol Effects.

FAS/E Support Network of B.C. (1997). FAS/E and Education: The Art of Making A Difference.

FAS/E Support Network of B.C. (1995). FASNET Screening Tool: For Use With Children Aged 0-18 Years. (5 Booklets).

FAS/FAE Prevention and Support Services Program, Patricia Centre of Children and Youth, Sioux Lookout. (1998). General Information and Intervention Strategies: Fetal Alcohol Syndrome/Fetal Alcohol Effects.

FAS/FAE Prevention and Support Services Program, Patricia Centre for Children and Youth, Sioux Lookout. (1998). Resource List of Materials: Fetal Alcohol Syndrome/Fetal Alcohol Effects.

FAS/FAE Prevention and Support Services Program, Patricia Centre for Children and Youth, Sioux Lookout. (1998). Resource List of Videos: Fetal Alcohol Syndrome/Fetal Alcohol Effects.

Normand, Claude and Rutman, Deborah. (1996). Caring for Children with Fetal Alcohol Syndrome. Child, Family and Community Research Program, School of Social Work, University of Victoria.

Normand, Claude and Rutman Deborah (1996). Working with Families Affected by Fetal Alcohol Syndrome/Effects. Child, Family and Community Research Program, School of Social Work, University of Victoria.

Normand, Claude and Rutman, Deborah (1996). Young Adults with Fetal Alcohol Syndrome: Experiences, Needs and Support Strategies. Child, Family and Community Saskatchewan Institute on Prevention of Handicaps. Two separate kits. Fetal Alcohol Syndrome: Prevention Resources and Fetal Alcohol Syndrome: Living and Working with Individuals with FAS. (date unknown).

Status of Women Council of the NWT Keeping Women and Communities Strong, Women, Substance Abuse and FAS/FAE: An NWT Needs Assessment, 1996.

8.3 Videos

David with FAS (1996) National Film Board of Canada.

Mother's Choice: A Thing Called Love (1995) Gryphon Productions.

Helping Families/Helping Children (1997) Yellowknife Association of Community Living.

Precious Gift (1993) Saskatchewan Institute on Prevention of Handicaps.

One Drink Won't Hurt My Baby Will It? (1996). Manitoba Association of Community Living.

Mary's Choice (1992) New York State Developmental Disabilities Planning Council.

The Thing Called Love (1993). Sacramento County Office of Education, Healthy Generations Healthy Learners, Prevention and Student Services Center.

9 Conclusions and Recommendations

As would be expected from an inaugural project related to an emerging issue, there are multitudes of conclusions and recommendations. In order to provide focus, four overarching conclusions have been identified. Each conclusion has one foundational recommendation, followed by a number of enabling recommendations.

9.1 FAS/FAE is a public health and social issue not simply a medical issue

The overwhelming conclusion from the literature, and validated in the pilot sites, is that FAS/FAE is not simply a medical issue. The impacts of social conditions, all the determinants of health and public policy are evidenced in the issues related to FAS/FAE identified by the pilot projects.

> *Considering the primary and secondary disabilities that accompany this birth defect, this is a huge and compounding public health problem. Strategies for prevention are of grave concern to individual families, to communities, to states and to the federal government...In order to protect children from the toxic effects of prenatal alcohol exposure an entire network of activities is needed, organized around the five Ps of prevention:*
> 1. *Public education*
> 2. *Professional training*
> 3. *Public policy*
> 4. *Programs and service*
> 5. *Parent and citizen activism (Streissguth, 1997, 250).*

9.1.1 Recommendation: Continue to work within a health promotion and prevention framework to address FAS/FAE.

FAS/FAE cannot be separated from the overall well-being of the individual, family and the community and this is influenced by economic, social, cultural and political circumstances. Addressing the broader social determinants and systemic causes of alcoholism in a community, poverty, violence against women, cultural breakdown, underemployment, poor housing and lack of access to health care are fundamental to preventing FAS/FAE. Efforts to prevent fetal alcohol syndrome must be seen in the overall context of improving the health status of Canadian women. Efforts to improve the health of young, poor women and families should reduce the incidence of alcohol-related birth defects in Canada.

- Include social and gender determinants of health in all program considerations
- Focus on mobilizing communities, not just CAPC projects
- Promote and support communities, families and individuals living with FAS/FAE working together

- Target family-centered, culturally sensitive awareness campaigns: teens, pregnant and parenting families, other languages
- Develop a consistent message related to alcohol abstinence during pregnancy
- Advocate for the inclusion of FAS/FAE in all provincial school health and professional education curricula

9.2 Early diagnosis is the key universal protective factor

The literature is clear that early and accurate diagnosis are key protective factors for children with FAS/FAE:

- *Our analysis revealed eight factors that were almost universally protective...having been diagnoses before 6 years of age (Streissguth, 1997,111);*
- *A medical diagnosis serves several major purposes: to facilitate communication among clinicians, to facilitate communication between clinician and patient (or parents)...and to guide treatment (Stratton et al, 1996, 63);*
- *An early diagnosis is one of the strongest factors associated with fewer secondary disabilities....Early detection empowers parents (and care givers) to plan creatively for their children with FAS/FAE as individuals and to obtain the services necessary to allow those children to develop to their best potential (Streissguth, 1997, 189).*

9.2.1 Recommendation: Facilitate early diagnosis and management of FAS/FAE

- Identify and address jurisdictional and infrastructure barriers related to diagnosis and management;
- Develop/adopt consistent diagnostic criteria: Clinical practice guidelines;
- Engage the physician community in diagnosis and management
- Make multidisciplinary diagnostic/management teams available to all areas;
- Provide broad training to physicians related to FAS/FAE recognition, diagnosis and intervention and to prevent recurrence in subsequent pregnancies;
- Train all primary health workers to recognize FAS/FAE to prevent secondary disabilities and recurrence in subsequent pregnancies;
- Provide for integrated treatment/intervention services;
- Focus on developing the strengths and capacities of children and families affected by FAS;
- Support parents/caregivers in implementing intervention plans;
- Coordinate training opportunities for CAPC staff related to screening, age-appropriate best practices for behaviour management and skill building.

9.3 CPNP and CAPC programs are key entry points to intervention

CPNP, Early Childhood and Head Start CAPC programs are natural places to nest FAS/FAE efforts. These types of programs provide a natural two-way linkage of community to child and family. Children and families are familiar with the setting and the personnel. CAPC programs and personnel offer a natural support system for both children and parents/caregivers. CAPC programs have the capacity to offer innovative interventions that can then be transferred to the home.

For the child, CAPC programs offer a place where the child's safety can be monitored and staff can be alert to risk factors such as poverty or abuse. CAPC programs are also able to work with very young children to help them establish boundaries and understand their limits. The routine and structure that CAPC programs provide in the lives of children living with FAS/FAE provides the predictability they need to develop to their potential. For Aboriginal children, the inclusion of the cultural perspective in early school experiences is seen as a protective factor. All of these reasons support the conclusion that CAPC programs are a key point of entry to intervention for children with FAS/FAE.

9.3.1 Recommendation: Continue funding for prevention and early intervention programming in Alberta CAPC projects.

- Sustain funding to pilot sites for 1-3 years; (See Sections 6.1.4, 6.2.4 and 6.3.4 for their specific needs and next steps)
- Implement action on feasibility study sites
- Conduct feasibility studies to determine capacities of both the project and the community, resource requirements and project model and plans, prior to funding;
- Provide adequate, stable funding to a limited number of projects;
- Focus on projects that promote communities, families and people affected by FAS/FAE working together
- Capitalize on opportunities for prevention with pregnant women and at-risk women into existing programs such as CPNP;
- Implement a monitoring and evaluation plan;
- Provide training and professional development to staff at all project sites;

9.4 FAS/FAE is a large issue requiring the collaboration of all levels of government and the private sector.

From the literature and from the experience of the pilot project, it is clear that FAS/FAE is an issue that is far too large for any one agency or government to tackle in isolation. FAS/FAE is a costly problem to treat and requires the human and financial resources of many sectors and disciplines. Without communication, cooperation and collaboration, FAS and other alcohol-related birth defects and developmental disabilities become structurally marginalized. This structural marginalization hampers meaningful progress and

FAS research, policy development and consequently service delivery suffers. FAS lies within the purview of many groups but is clearly not the full responsibility of any one.

Without the cooperation and collaboration of all levels of government and the private sector, comprehensive prevention, diagnosis, and treatment goals cannot be approximated. The challenge is to improve coordination and integration among health, education, social services, community agencies, families and government agencies. Preventing FAS/FAE and treatment of primary and secondary disabilities must be a high and long-term priority at the federal and provincial levels of government.

9.4.1 Recommendation: Health Canada continue to collaborate with all levels of government and the private sector to address FAS/FAE.

Health Canada recognizes FAS/FAE as a national health concern for individuals and society. Currently, the department is collaborating with provincial and territorial governments, aboriginal organizations, associations of health professionals, researchers and various other non-governmental organizations in dealing with this serious problem. Initiatives such as the co-funding of the Canadian Centre on Substance Abuse Clearinghouse, the 1996 Joint Statement on *The Prevention of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)*, the development of the Canadian Perinatal Surveillance System and the integration of FAS prevention and early intervention into community-based initiatives such as the CPNP and CAPC programs demonstrate the federal governments commitment to addressing FAS/FAE (Terms of Reference, Departmental Coordination Committee on Substance Use During Pregnancy, 1997).

In keeping with the current strategic direction of Health Canada, the following is recommended for consideration:

- Initiate the development of an FAS/FAE infrastructure model that would include primary prevention, early detection and medical/clinical expertise (See Section 2.5.1.1 for a discussion of models);
- Advocate for the development of Family Resource Centres embedded in local communities. These Centres would organize around advocacy, training, service provision, respite and resources. The Centres could be either multi-focus or specific to FAS/FAE.
- Advocate for the development of a Clearinghouse responsible for the communication and coordination of research, intervention and evaluation strategies for primary, secondary and tertiary prevention;
- Advocate for the development of a national surveillance system for the reporting of FAS/FAE
- Advocate for the provision of "lifelong wrap-around" services for children diagnosed with FAS/FAE;
- Advocate for public policy changes necessary to provide quality services to children with FAS/FAE, specifically: changes to educational funding for classroom aides to

include FAS/FAE as a qualifying diagnosis and changes to social services and/or healthcare funding to provide funding for the initial diagnosis, including the neuropsychological assessment.

9.5 Summary

In summary, the project has allowed two communities to begin to address FAS/FAE in ways that are meaningful to them. Two sites have been assessed to determine the feasibility of locating FAS/FAE projects in them. A comprehensive resource collection has been obtained. Recommendations, while directed to Health Canada, require the collaboration of all levels of government and the private sector to address. The tragedy of FAS/FAE is entirely preventable, children need not suffer the lifelong consequences of prenatal alcohol exposure. An informed and compassionate public in concert with community leaders and advocates, policy makers with all levels of government, researchers and politicians must be catalysts for social action and change to eliminate FASE/FAE.

Our final thoughts and feelings about this project are best captured in the words of Dr. Ann Streissguth, a leading researcher and advocate for FAS/FAE prevention and effective intervention with children and families:

> *I have never met a woman who drank during pregnancy because she wanted to hurt her child or because she didn't care….If communities are to prevent fetal alcohol damage to children, they must begin by extending services to high-risk women and mothers that focus on reducing alcohol intake, increasing family planning, advocating for mothers and ensuring safety for children (1997,p. 264).*

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Appendix A Proposal to Health Canada

FAS/FAE

1.0 Introduction

Fetal Alcohol Syndrome has been recognized as one of the leading causes of preventable birth defects and developmental delay in children.
The task is to explore the feasibility of piloting an FAS/FAE Project in Alberta.

2.0 Background Review

Reviewed two FAS/FAE Projects
1) Support for FAS Children and their Families, Yellowknife, NWT

- a CAPC project that provides prevention activities by promoting FAS/FAE education/awareness and facilitating community action in developing effective community-based family supports for those families with FAS/FAE children
- an outreach model with Aboriginal Outreach Staff and a Coordinator
- developed educational resources (video to be used in a plain language workshop which is a facilitator lead educational program) and planning to develop an FAS/FAE module to be incorporated with Nobody's Perfect
- acceptance of the issue has been a barrier for this project so they have had to develop ways to work within the community in a non threatening way

2) FAE Program, Winnipeg, MB

- a CAPC project that works directly with children diagnosed with FAE/FAS and their parents or caregivers and with inner city pregnant women
- an early intervention model that has a diagnostic team
- developed assessment strategy's/ tools completing extensive research reviews

Reviewed the Joint Statement: Prevention of FAS/FAE in Canada
This document is a collaborative effort of Health Canada, many medical/nursing associations, aboriginal and multicultural groups, and other organizations known for their work in this area. The area of "Prevention Efforts" identified in the report can provide a useful framework to examine the scope of prevention efforts:

- **Primary Prevention** - actions that avert the health problem by developing education/awareness efforts and population health strategies addressing the determinants of health

- **Secondary Prevention** - actions that identify pregnant and childbearing women who may be at risk for having a child with FAS/FAE and developing screening and early intervention strategies and programs to prevent alcohol related birth defects and developmental delays in children

- **Tertiary Prevention** - actions that: a) prevent the recurrence of the condition in a subsequent child with a family who already has a child affected with FAS/FAE, and, b) treatment of children with the condition to lessen the developmental effects. Strategies at this level are assessment, diagnosis, and intervention.

3.0 Prevention Efforts in CPNP/CAPC Programs in Alberta

The CPNP projects work with pregnant women and their infants up to twelve months with numerous factors that place the women more at risk for an unhealthy pregnancy outcome, with one of the factors being substance abuse. The projects have actions and strategies that are mainly focussed on **Secondary Prevention**, that is, education and prevention efforts directed toward targeted women to assist them to have a healthy baby.

The CAPC projects work with at risk children from birth to age six and their families. The projects have actions and strategies that are mainly focussed on **Secondary and Tertiary Prevention**, that is, approaches such as Head Start, Home Start, Home Visits, Parent Education/Support Programs or a combination of these approaches that improve the developmental capacity of targeted children and foster healthy parent/child interactions.

CPNP and CAPC projects are logical platforms from which to build on their existing strengths and enhance current programming to provide actions and strategies to both increase awareness and behaviours around FAS/FAE prevention and to provide early intervention support to families with children identified as FAS/FAE to lessen the cognitive, behavioural, and social impact of the diagnosis.

4.0 Overall Goal, Objectives, and Outcome

To develop, implement, and evaluate within selected CAPC/CPNP sites, an FAS/FAE pilot project that will enhance and/or introduces:

- **Secondary Prevention** efforts of FAS/FAE education/awareness for pregnant women and women of childbearing age at risk for having a child with FAS/FAE to promote motivation for behavioural change

- **Tertiary Prevention** efforts of early intervention programming with children identified with FAS/FAE to lessen the developmental impact and with their caregivers to provide support

This is a first step in reaching the long term goal of building capacity in all CAPC/CPNP programs in Alberta in FAS/FAE prevention with the outcome of reducing the significant health effects of FAS/FAE in children.

4.0 Activities and Timelines

ACTIVITIES	TIMELINES
A CAPC organization with both CPNP and CAPC funding or a link with CPNP will: ♦ sponsor the FAS/FAE pilot project ♦ manage the administration of the funds ♦ coordinate two FAS/FAE CPNP/CAPC meetings during the pilot ♦ ensure a community perspective	October 1997 and ongoing
An Advisory/Steering Committee for the pilot project will be established to: ♦ provide representation from practitioners, agencies, researchers, governments ♦ bring expertise in the area of FAS/FAE ♦ build on partnerships and work already occurring in Alberta ♦ provide support, direction, and guidance to the pilot project	October 1997 and ongoing
Selected CAPC/CPNP sites will: ♦ implement **secondary prevention** efforts that target women before and during their childbearing years and **tertiary prevention** efforts that target children suspected of or diagnosed with FAS/FAE ♦ represent diverse geographical areas of the province ♦ have a link to both CPNP and CAPC projects within their communities ♦ work in Aboriginal communities ensuring culturally sensitive direction during the pilot ♦ provide direction and feedback to the consultant(s)during the pilot ♦ participate in two FAS/FAE meetings at the beginning and end of the pilot	November 1997 - March 1998
A consultant or consulting team with expertise in FAS/FAE, early childhood development, community development, and evaluation will:	
♦ provide background research on effective FAS/FAE program models identifying best practises of successful programs ♦ review and obtain a sample of effective FAS/FAE tools and resource materials that could be tested during the pilot at the sites	early November 1997
♦ facilitate two meetings at the beginning and end of the pilot with key CAPC/CPNP projects to solicit feedback on programming, models, resources, implementation and training needs	November 1997 and March 1998
♦ develop a strategic plan and evaluation plan for implementing the FAS/FAE prevention interventions in the selected CAPC/CPNP sites	December 1997
♦ provide site-based consultation to the sites in program adaptation, resource adaptation, staff training, child development, etc. during the implementation phase	December 1997 - March 1998
♦ produce a final process evaluation report and make recommendations for implementation beyond the pilot phase	April 1998

5.0 Proposed Budget

The budget would contain personnel costs of coordination and implementation at the selected CAPC/CPNP sites and contractual fees for the consultation team, material costs for the FAS/FAE resources, evaluation and dissemination, travel and meeting costs. **TOTAL: $175,000.00**

1.0 INTRODUCTION

This proposal is submitted in response to the request for services from Health Canada to explore the feasibility of piloting an FAS/FAE Project in Alberta. Equitable Consulting Services is proposing to work closely with Health Canada to oversee the development and implementation of the initiative. We will bring to the project a multi-disciplinary approach by involving a team of consultants to assist with the initiative.

The role of the consultant team will be to work collaboratively with program stakeholders. We will provide a theoretical and conceptual framework, program planning and implementation based on best practices, resource acquisition and adaptation, staff training and evaluation expertise to the selected sites involved with the pilot project. We expect the scope of the project to include between 2 - 4 sites and the length of the pilot to be approximately 6 months. These expectations are to be reviewed and finalized with Health Canada.

2.0 GENERAL APPROACH

Health Canada has identified a goal to develop, implement, and evaluate within selected CAPC/CPNP sites, an FAS/FAE pilot project that will enhance and/or introduces secondary and tertiary prevention efforts into existing prevention and early intervention programs. These programs work with pregnant women and their children to improve the likelihood of positive outcomes in healthy child development and parent/child interactions.

It makes good sense to build on the strengths and capacities of existing programs operating within the province of Alberta. The pilot is intended to work with selected program sites with the long term goal of building agency capacity in all CAPC/CPNP programs in FAS/FAE prevention. The anticipated outcome of the project is the reduction of significant health effects of FAS/FAE in children.

FAS/FAE is a complex problem with several gaps in knowledge. For instance, there is no national data on fetal alcohol syndrome or fetal alcohol effects and there are a number of contentious issues which emerge in the literature. There are no easy or straightforward answers or strategies to address this difficult issue. There is a growing consensus that the best line of defence is prevention and early intervention with women before and during their child-bearing years and also at their partners and the community (National Council on Welfare, 1997). In light of these factors, several underlying principles will guide our approach:

collaborative in process (consensus building)
multi-disciplinary in approach
culturally sensitive
gender, social and economic determinants analysis
build on the strengths and capacities of the selected sites
family centred and community focused
holistic and innovative

3.0 WORKPLAN

Phase One: November - December

Project Planning and Coordination

Finalize project design, timelines, terms of reference of the evaluation with Health Canada

Identify preliminary issues, key stakeholders, liaise with Project Sponsor, Advisory Committee

Identify and liaise with other local and provincial FAS/FAE initiatives

Attending upcoming CAPC workshop (Edmonton) and 2 day seminar on FAS/ FAE (Calgary)

Conduct literature review and analysis

Begin phase one of process evaluation and documentation

Phase Two: December - January

Project and Organizational Development

Consult with Health Canada regarding selection process and criteria

Consultation and site visits with Sponsor and selected site(s) to solicit input on program needs, internal capacities and vision for the program

Finalize clinical and research literature review

Identify models and best practices

Resource acquisition and adaptation

Continue with evaluation

Phase Three: January -March

Project Implementation and Monitoring

Finalize site selection

Liaise and consult with project stakeholders and Health Canada concerning all facets of the project implementation

Monitor learnings from sites and respond to emerging and site-specific needs

Transfer and share the key learnings, central issues, challenges, best practices from site to site, adjust program component as required

Phase Four: April - May

Project Completion

Continue consulting and liaise with Project stakeholders and Health Canada

Final site visits to solicit feedback on programming implementation and results

Draft final report

Final evaluation report with recommendations beyond the pilot phase

4.0 TIMELINES

Activity	Time Allocated
Project Planning and Coordination	
Meetings and consultation with Health Canada (two days per month)	10 days
Meetings and Consultation with Advisory/Steering Committees	10 days
Out of town travel and site visits	10 days
Developing the Framework	
Collection and Review of Clinical and Research Literature	10 days
Attendance at workshops and related meetings (CAPC/CPNP)	06 days
Collection and Review of Program Models/Strategies	07 days
Analyze Program Models and Best Practices/Evaluation Research for adaptation to pilot sites	10 days
Project Implementation	

Provide site-based consultation to the sites in program adaptation, resource adaptation, staff training, child development during the implementation phase	30 days
Consultant Team Meetings (two days per month)	10 days
Project Evaluation	
Conduct and write final process evaluation with recommendations for implementation beyond the pilot phase	44 days
Total Consulting Days Allocated	**147 days**

5.0 BUDGET

Consulting Fees:	$46,350.00
Special Advisory Fees:	$5000.00
Evaluation Fees:	19,800.00
Travel:	$10,000.00
Resource Acquisition and Compilation:	$16,350.00
Professional Services for Feasability Studies:	$15,000.00
Project Administration Costs:	$12,500.00
TOTAL BUDGET:	**$125,000.00**

PROPOSED SCHEDULE OF PAYMENTS

Upon signing contract:	30%	$33,750.00
Upon verbal interim report:	30%	$33,750.00
Upon submission of Draft Final Report:	30%	$33,750.00
Upon completion of project:	10%	$11,250.00
Total Payments:		**$112,500.00**

6.0 PROJECT DELIVERABLES

For this project, the consultants will:

- Consult on all aspects of the planning, project development, implementation and evaluation phaseof the pilot project.
- Work closely with the managers and staff of Health Canada and provide timely information concerning the activities, progress and status of the project (scheduled monthly meetings).
- Present a verbal interim report on the status of the project to Health Canada (at an agreed upon time)
- Consult with the site managers, staff, advisory groups involved with the pilot project concerning all aspects of the project. This includes providing information, staff training, resource materials, program models and best practices, community development issues and evaluation.
- Provide a Resource File on FAS/FAE
- Prepare a final process evaluation report of the project including recommendations
- Will complete the assignment by April 15, 1998. *

*Timelines are subject to review and approval by Health Canada

7.0 SPECIAL ADVISORS

We propose to involve five specialists with experience in FAS/FAE*. The following disciplines will be represented:

- Developmental Pediatrician
- FAS/FAE and Addictions Research and Evaluation
- Aboriginal Health Promotion and Community Development
- Prevention and Early Intervention / Healthy Child Development
- Child Welfare/ Foster Care

* The names of individuals to be finalized and agreed upon by Health Canada.

8.0 FAS/FAE PILOT PROJECT PROPOSED SELECTION CRITERIA FOR PILOT SITES

- Established CAPC program or connection to CPNP funded project
- Culturally sensitive
- Geographical diversity (north, central, south)
- Urban/Rural
- Organizational Stability and Capacity to complete pilot phase
- Community Capacity and Resources
- Identified need and desire to be involved with pilot project and process
- Agrees to work with consultants and take part in formal evaluation
- Ability to travel (minimum 2 meetings)
- Agrees to project management sponsor and budget

Appendix B Evaluation Plan

FAS/FAE Prevention Project

Proposed Evaluation Plan

1.0 Introduction

Health Canada, Health Promotion and Programs Branch requires that an evaluation be conducted of the FAS/FAE Pilot Project taking place in Alberta. Information generated by this evaluation would be used to guide the development of the second phase of this project. It is anticipated that as the evaluation proceeds, new information will give rise to the need to modify the proposed evaluation plan. To that end, the following evaluation approach should be viewed as an initial plan, not as a final and closed method.

Our approach to the evaluation would be to combine our evaluation expertise with the content expertise of Senior Staff, Project personnel, Advisory Committee members and Site facilitators. Because we value a collaborative approach, we would look forward to working with these individuals to provide a useful and useable evaluation.

2.0 Evaluation Design

To evaluate the management, process, outcomes and impact of the FAS/FAE Pilot Project, a multifaceted approach is proposed. The goals outlined below provide direction for the collection and analysis of evaluation data. The goals .follow a description of the proposed data collection methods.

2.1 Document Review

In collecting data for the evaluation, there are a wide variety of documents to be reviewed. The naming of many documents will occur only after the commencement of the Project. However, it is anticipated that planning committee minutes from each site will be recorded. Further, it is suggested that each Site facilitator keep a log which would also be reviewed. Tracking records are expected to be kept for program participants, requests for information, resource utilization, and other items that emerge from the programming.

It is anticipated that document review will provide the underpinnings of the evaluation. Document review will also inform recommendations, as information from other locales, governments, and the project are integrated.

2.2 Site Visits

Site visits will allow the evaluator the opportunity of observing program components first-hand. The specific information to be gathered from such visits will emerge as the project proceeds.

2.3 Key Informant Interviews/ Focus groups

As the evaluation progresses, it is anticipated that a number of stakeholders will be identified, whose opinions related to FAS/FAE prevention will be desires. It is not possible to identify the specific mode of contact at this point. A combination of key informant interviews and focus groups will be used to gather information from these stakeholders. A preliminary list of stakeholders includes, but is not limited to the following:

- Senior Staff of HPPB
- Project Personnel
- Advisory Committee Members
- Candora Staff
- Site Facilitators
- Program Participants
- Site specific community leaders

In summary, a wide variety of data gathering methods will be utilized in this evaluation. The following chart outlines the evaluation goals and the activities proposed to meet the goals.

EVALUATION GOALS	DATA COLLECTION METHODS
1.0 Historical Context 1.1 To describe the historical development of the FAS/FAE Pilot Project 1.2 To describe the environmental climate of the pilot sites at the inception and throughout the project 1.3 To document baseline information related to capacities, needs, barriers, and programs at each pilot site	Document review Site visits Key Informant interviews: Site Stakeholders, Project Consultants, Senior Staff
2.0 Program Management 2.1 To evaluate the use of staff, contract personnel, and material resources at pilot sites 2.2 To determine the appropriateness of systems established to co-ordinate, monitor and evaluate Project activities at pilot sites 2.3 To document the project development process for pilot sites 2.4 To determine strengths and weaknesses of the project development process utilized at pilot sites 2.5 To evaluate the effectiveness of the community capacity building process at pilot sites 2.6 To document resource utilization 2.7 To evaluate the role of the Project Advisory Committee	Document review: • Planning minutes/logs • Planning documents • Site facilitator logs • Resource utilization tracking Key Informant interviews: Senior Staff, Project Personnel, Site Facilitators, Community Stakeholders, Advisory Committee Members

EVALUATION GOALS	DATA COLLECTION METHODS
3.0 Program Outcomes 3.1 To describe the programs developed for the project at each pilot site 3.2 To determine if the programs reached their target groups at each pilot site 3.3 To identify the demographic trends in various programs' participants 3.4 To determine if the programs increased accessibility to secondary and tertiary FAS/FAE prevention, noting those that are less adequately served physically and/or culturally 3.5 To describe 'out of program' requests for additional information/services 3.6 To determine the nature of partnerships developed by each pilot site 3.7 To determine if the pilot projects increased the community support for FAS/FAE prevention 3.8 To identify the sustainability of programs at each pilot site 3.9 To identify unintended outcomes	Document review • Program component tracking • Pilot site reports Key informant interviews: Site Facilitators, Project personnel Emergent from site visits
4.0 Program Impact 4.1 To describe the short term effectiveness of the various pilot site programs and activities 4.2 To describe participant satisfaction with various programs and activities 4.3 To document media coverage related to FAS/FAE prevention	Document review: • Participant satisfaction instruments • Media tracking • Site Facilitators' logs Key Informant interviews: Site Facilitators, Program Participants, Project Personnel Emergent from Site visits
5.0 Future Directions 5.1 To identify municipal, provincial and federal trends in FAS/FAE prevention that would influence the effectiveness of future programming 5.2 To identify problems, barriers, conditions or issues which could influence the quality or quantity of future FAS/FAE programming 5.3 To provide recommendations for FAS/FAE prevention programming beyond the pilot phase	Document review: • Literature • Government documents Key Informant interviews: Senior Staff, Project Personnel, Site Facilitators

3.0 Reports

A verbal interim report will be provided at an agreed upon time.

A Final Report will be delivered by April 15, 1998. The structure of the Final Report will be similar to the following:

Executive Summary
Table of Contents

Chapter 1	Introduction: CAPC Framework; Project Description
Chapter 2	Evaluation Approach
Chapter3	Analysis and presentation of Findings: Site I
Chapter 4	Analysis and presentation of Findings: Site 2
Chapter 5	Meta analysis of all sites
Chapter 6	Feasibility study of Calgary sites
Chapter 7	Recommendations and Conclusions

Appendix C Framework for Data Collection

Framework for Data Collection/ Interview Guide/ Site Visit Guide:

Baseline Data collection

- Current Programs/Services offered by Pilot Sites
- FAS in local context:
    - Prevalence: in Pilot Site programs and community
    - Behaviours
    - Contributing factors
- Current Diagnostic Process
- Current FAS-specific programming at Pilot Site
- Current community FAS programming, services and resources:
    - Programs, including support groups & group homes
    - People
    - Print/media
- Knowledge re FAS:
    - Pilot Site staff
    - Parents
    - Professional Community
    - Public awareness
- Source of knowledge re FAS:
    - Pilot Site staff
    - Parents
    - Professional Community
    - Public
- History of community collaboration:
    - Re FAS
    - Re other issues
    - referral patterns for Pilot Sites
- Gaps/Barriers in FAS services and programs

Final Evaluation

5 guiding questions:

1. Did we do what we said we would do?
2. What did we learn about what worked and what didn't work?
3. What difference did it make that we did this work?
4. What could we do differently?
5. How do we plan to use evaluation findings for continuous learning?

Appendix D Key Informants

Key Informants

Fort McMurray:

- Edna Olsen, The Children's Centre
- Christine Petersen, The Children's Centre
- Ann Dow Clark, Office of the Commissioner of Services for Children/Families
- Debbie Martin-Cox, Alberta Family & Social Services
- Lynda McLellan, Community Mental Health Services, Northern Lights Regional Health Centre
- Karin King, AADAC
- Laurel Duncan, Foster mother, & Keyano College
- Beth Jodrey, Pre/Post Natal Coordinator, The Children's Centre
- Edith Nichols, Aboriginal Family Visitor, The Children's Centre
- Tony Clarke, WB Youth Association Mentor Program
- Cindy Punko, Pre-school teacher, The Children's Centre
- Betty Power, Pre-school teacher, The Children's Centre
- Cheryl Karanjia, Pre-school teacher, The Children's Centre
- Dan Mullen, Start Program, Resource Library Coordinator
- Tracy Nunns, School programs Coordinator- Drama, posters, radio announcements
- Shelly Janvier, Rural pre-school teacher, The Children's Centre
- Michelle Shears, Rural pre-school teacher, The Children's Centre
- Theresa Perrier, Rural pre-school teacher, The Children's Centre

Lethbridge:

- Francis Weaslefat, Native Women's Transition Home
- Dolly Creighton, Project Facilitator
- Devi Herman, AADAC
- Evelyn Goodstriker, Kainai Educational Society
- Dr. Deborah Pace, Kainai Educational Society
- Heather Meece-Zimmers, Chinook Health Region, Children's Health Resources
- Francis Bogle, Lethbridge Family Services
- Murray Armstrong, Lethbridge Family Care
- Cheryl Williams, Lethbridge Family Care
- Hazel Mitchell, Lethbridge Community College

Other

- Liz McDougall, Health Canada
- Carol Oliver, Equitable Consulting
- Healther White, Equitable Consulting
- Larry Svenson, Alberta Health, Health Surveillance
- Dr. Suzanne Tough, CRHA

Appendix E Fort McMurray Site Project Material

THE CHILDREN'S CENTRE
FETAL ALCOHOL SYNDROME / EFFECTS INITIATIVE

The Children's Centre received $25,000 from Health Canada in January/98 for an FAS/FAE initiative in Fort McMurray. The Northern Lights Regional Working Committee on FAS began meeting in December/97, and by January had developed a plan for a community initiative. The working committee of 14 people from various agencies in the community, met four times over the next three months to organize, and carry out the initiative.

The Children's Centre, and the Northern Lights Regional Working Committee on FAS completed the following activities that brought the issue of FAS/FAE to the attention of our community:

FAS Workshop in Maple Ridge

Three employees from The Children's Centre attended the Fetal Alcohol Syndrome workshop in Maple Ridge B.C. in January. This workshop assisted in giving us a framework, and contacts for our own conference, and provided us with good information on FAS/FAE.

FAS/FAE Resource Library

We contracted with an individual to develop a solid, and usable resource library on the issue of FAS / FAE. This person planned, purchased, and catalogued a library specific to FAS/FAE. This resource library will be housed in the Provincial Building on the 9th floor. The actual space will be provided by C.H.O.I.C.E.S., a non-profit agency that has participated in this FAS initiative. The resource library will be available to the public, and professionals. It is our understanding that it will be the most comprehensive in Alberta, and possibly in western Canada. We will be continuing to advertise the existence of these materials so that it will be used to it's potential.

Community Awareness and Community Engagement

We thought that the best way to engage the "target group" of early to late adolescents would be to find ways of having them directly participate in this initiative. We contracted with an individual to coordinate, organize, and complete the following activities:

1) To have the Westwood High School Drama group script, and present an improvisational type of production on the issue of FAS/FAE , and drinking during pregnancy. This production will be presented to other schools throughout the early spring. A number of foster parents, and community workers have agreed to attend these productions to answer questions and provide information on the issue.

2) To have the High School drama group create public service radio spots that would catch the attention of that age group, and hopefully initiate conversation/thought about the FAS issue.

3) To complete a poster contest throughout the junior and high schools focused on the drinking during pregnancy issue. The winning posters will be reproduced, and displayed in the community.

FAS / FAE Conference in Fort Mcmurray

We obtained the services of Mary Vandenbrink, a knowledgeable and well-known speaker on FAS, to travel to Fort McMurray and provide a one-day conference on this issue. We also had a panel of local individuals who had some experience with children/young adults with FAS. The conference was held March 21st at the Father Turcotte School Gym. The conference was free of charge, and the people attending ranged from birth parents of FAS/FAE children, foster and adoptive parents, to community professionals in the areas of education, social services and health. This conference was very successful, and 146 people from the community attended. The general response from people who attended seems to be that more conferences of this type are needed in our community.

Staff Workshop

We intended to bring a "specialist" in this field to Fort McMurray to spend a full day or two with our teachers and outreach workers. Because of the short time span available for this initiative, the people we contacted were unavailable. However, we did have the Public School Special Education Consultant provide a presentation to our staff on this issue. This is one activity that we would still like to pursue if this initiative continues into the next fiscal year.

FAS/FAE BOOK LIST

Alcohol, Pregnancy And The Developing Child		Spohr & Steinhausen
The Broken Cord		Michael Dorris
Development of the Central Nervous System Effects of Alcohol and Poiates		Michael W. Miller
The Enduring Effects of Prenatal Alcohol Exposure on Child Development		Streissguth, Boodstein, Sampson, Barr
Fantastic Antone Succeeds		Judith Kleinfeld Siobhan Wescott
Fetal Alcohol Syndrome		Ernest L Abel
Fetal Alcohol Exposure and Effects		Ernest L Abel
Fetal Alcohol Syndrome Overcoming Secondary Difficulties		Ann streissguth Jonathan Kanter
Fetal Alcohol Syndrome From Mechanism to Prevention		Ernest L. Abel
New Literature on Fetal Alcohol Exposure and Effects		Ernest L. Abel
Reaching Out to Children with FSA/FAE		Diane Davis
A Poison Stronger Than Love The Destruction of an Ojibwa Community		Anastasia M. Shkilnyk
Prenatal Exposure to Drugs/Alcohol		Jeanette M. Soby
Yes, You Can A Guide to Empowerment Groups		Charlotte Davis Kasl
Peer Support	Facilitator's Guide Resource Bibliography Tape - 6:10 minutes	AADAC
Fetal Alcohol Syndrome/ Fetal Alcohol Effects	Strategies for Professionals	Diane Malbin
INFO SHEETS	ABC of Alcohol ABC of FAS and other Alcohol-related Birth Defects ABC of FAS and other Alcohol-related Birth Defects - from infancy to adulthood	

ABC of FAS and other Alcohol-related Birth Defects: Intervention Strategies

Advice from the Sidelines

The Effect of Toxic Substances on Development

The 12 Steps of Understanding ARBD

The ABCs of Fetal Alcohol Syndrome and Other Alcohol-related Birth Defects

Best Start - Prevention of Low Birthweight in Canada

How to Take Care of Your Baby Before Birth

FAS Regional Contacts

A Constant Juggling Act

A Long-Term Perspective of FAS	Ann P. Striessguth
About FASE Secondary Disability Study Fetal Alcohol Syndrome - Diagnosis, Epidemology, Prevention and Treatment	FAS/E/Support Network of B.C.
Alcohol Related Birth Defects	Office of the Commissioner of Services for the Services for Children and Families
Alcohol and Pregnancy	AADAC
Alcohol in Alberta: Perspectives on Its Use and Effects	AADAC
Alcohol and Pregnancy - Some resources Available in Canada	AADAC
Beyond the ABCs: Information for professionals	AADAC
Characteristics of FAS/FAE	Patricia Tanner-Halverson
Clinical Recognition of FAS	Jon M. Aase
Community Mobile Treatment: What It Is and How It	AADAC

Works	
Definition of Fetal Alcohol Syndrome and Fetal Alcohol Effects	Iceberg
Counseling FAS/FAE Children and Their Families	Diane Davis
Parents Who Are Also Professionals: It May Not Be What You Think	Diane B. Malbin
Using Structure and Consistency With High Activity Toddlers	Kathleen Dyer
Suggestions for School Districts	Donna M. Burgess
The Long Road: Educating Students with FAS or FAE	Donna Burgess and Ann Striessguth
Recommendations From the American Academy of Pediatrics	
Fetal Slcohol Syndrome and Fetal Alcohol effects: A Lifespan View, with Implications for Early Intervention	Heather Carmichael Olson Donna M. Burgess Ann P. Streissguth
The FAS/FAE Child in the Classroom	Diane Davis
Guidelines for Intervention with Families and Children with FAS/FAE	Heather Carmichael Olson Donna M. Burgess Ann P. Streissguth
Keys to Intervention	Heather Carmichael Olson Donna M. Burgess Ann P. Streissguth
Where Do You Begin When You Have a Child With FAS/FAE?	Larry Gellerstein
The Suquamish Tribe Honors Pregnant Women	Lisa Giles Donna Jones-Coleman
Alcohol & Pregnancy Activities in Canada: They Don't All Cost Money	Ann P. Streissguth
Community Obstacles Facing High-Risk Mothers: The Birth to 3 Project	Ann P. Streissguth, Therese Grant, Cara C Ernst, Pam Phipps, Beth Gendler
Red Bow Team At Work	Pat Borman, Pam Hamon
What You Can Do To Make a Difference	Sandra P. Randels
FAS/FAE: Sources of Information and Support	AADAC

Community Resource List

Fetal Alcohol Syndrome/Effect Children: Resource List	AADAC
FAS/FAE Information Service	AADAC
Fetal Alcohol Syndrome: An Issue of Child and Family Health	CCSA National Working Group on Policy
Fetal Alcohol Syndrome & Other Alcohol Related Birth Defects	AADAC
Effects of Prenatal Exposure to Alcohol Across the Life Span	Paul D. Connor Ann P. Streissguth
Intervention and the Child With FAS	Lyn Weiner Barbara A. Morse
Joint Statement: Prevention of Fetal Alcohol Syndrome (FAS) Fetal Alcohol Effects (FAE) in Canada	Health Canada
Manitoba Medical Association - FAS - Tape 3x30 sec	
Myths and Misunderstandings About Fetal Alcohol Syndrome (FAS) And Fetal Alcohol Effects (FAE)	
Student Assistance For Everyone	AADAC
Strategies for Educating Children With FAS/FAE	Patricia Tanner-Halverson
Survival Skills For Parents of FAS/FAE Children	Patricia Tanner-Halverson
Teaching Students With FAS & Possible Prenatal Alcohol-related Effects	Alberta Education/Special Education Branch
The "Facts About FAS/E"	It Takes a Community
Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects(FAE)	Ann P. Streissguth, Helen M. Barr, Julia Kogan, Fred L. Bookstein
Young Adults With Fetal Alcohol Snydrome Or Fetal Alcohol Effects: Experiences, Needs and Support Strategies	Brenda Copeland Deborah Rutman

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TAPES

David with F.A.S. X 2

FETAL ALCOHOL INITIATIVE

FUTURE CONSIDERATIONS:

Time lines were too short and conflicted with our agencies year end and the heavy work load an agency is under at this time of year.

There was no compensation for administration (time, wages etc..). Executive Directors plus Program Coordinator's costs.

Although very supportive, there were too many key people that we were responsible to, who required the same information. Visits were not coordinated.

With the amount of money we received we knew that there were tasks that we would like to accomplish, however the time frame made it impossible to undertake, i.e.: bringing in a person or person's to provide education and ideas specifically with our staff in our programs, who are working directly with F.A.S. children and parents.

There was no opportunity to try out different ideas in our classrooms/programs and to have the time to evaluate the implementation of the programs and ideas.

Pilot was to be 6 months however, it really was undertaken over a 3 month time frame. This pilot should in fact be undertaken over a 1 year time frame.

If our NLRW group was not getting off the ground at about the same time as this pilot, we do not believe that we would have been as successful as it would have taken more time to truly make it a community initiative.

We appreciated being considered for this pilot and are very pleased with what we have accomplished in a very short time period. Keeping in mind that we can be much more effective if we have more workable time frames, we would welcome opportunities for future funding in this area, which would continue to support our community initiative on F.A.S..

Appendix F Lethbridge Site Project Material

FAS / FAE PILOT PROJECT
HEADSTART PROGRAM - Lethbridge, Alberta
WORKPLAN
IN THE DEVELOPMENT OF A PROTOCOL - PROCESS
APRIL 27, 1998

The Children's Services with the Headstart Program will need to undergo some progam changes that will effectively identify and deliver programs specifically focussing on "special needs children". The FAS / FAE Pilot Project (December 1997 to March 1998) idenitifed the need for the development of a Protocol - Process that will provide a program for children at risk which will include:

ASSESSMENT > DIGNOSIS > INTERVENTION

The following is a summary of the activities that will be required and are necessary before the program (protocol - process) can be delivered:

TEAM: Dolly Creighton, *Project Coordinator*, Frances Weasel Fat, *Administrator For Society;* Dorris Sweet Grass & Charlotte White Quills, *Headstart Program Staff;* Dr. Linda Storoz, Pediatrician;Dr. Deborah Pace, *Psychologist.*

ACTIVITY	PERSON RESPONSIBLE	TIMELINE
1. Policy development for Headstart Program which include the need for early intervention and identification of "children at risk"	Headstart Teaching Staff Administration of Society Board Of Directors Of Society Project Coordinator	May 1998
2. Documentations to be developed for Individual Education Program Plans including: i) Parental Consent Forms ii) Release Of Information Forms iii) Progam & Services - consent forms iv) Referral Forms to Specialists: Dr. Storoz, Pediatrician & Dr. Pace, Psychologist	Project Coordinator with Team	May 1998
3. Inservice and Training for all Staff and Administration on the "Identification Process and Assessment Protocol"	Project Coordinator (Elders To Be Involved In Cultural Training Aspect)	June 1998
4. Registration and Parental Inservice Information Including: a) Program(s) b) Assessment(s) c) Referrals To Specialists d) Program Design & Delivery	Headstart Staff & Administration with Project Coordinator	August 1998
5. Initial Screening Procedure For All Students At Headstart.	Headstart Teaching Staff (May Involve Childrens' "CARE" Centre)	September 1998
6. Assessement & "Case Conferencing" with the Individual Program Plan Team for the student assessed by the Specilaist(s).	Dr. Deborah Pace, Psychologist Dr. Linda Storoz, Pediatrician	September 1998
7. Evaluation Of Protocol - Process	The Whole Team	Dec. 1998

FAS / FAE PILOT PROJECT

PROTOCOL / PROCESS DEVELOPMENT

WORKING PAPER

FIRST MEETING TO BEGIN THE DEVELOPMENT OF PROTOCOL - PROCESS

DATE: APRIL 6, 1998

PLACE: DR. STOROZ'S OFFICE

ATTENDANCE:

Dr. Storoz, *Pediatrician*
Dr. Pace, *Psychologist*
Frances Weasel Fat, *Administrator Of Native Women's Transition Home SOCIETY*
Doris Sweet Grass, *Headstart Program Coordinator*
Charlotte White Quills, *Headstart Teacher*
Edna ~~**Wendy,**~~ Parents As Teachers
Dolly Creighton, *FAS/FAE Pilot Project Coordinator*

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Company: ____
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Comments: ____
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LIST OF STAKEHOLDERS

* Biological Parent: Mother & Father
* Extended Family (N.B. For information purposes)
* Foster / Adoptive Parents
* Teachers: Playschool - Headstart
* Social Services: Child Protection - Financial Needs - Day Care - MCS
* Physicians: Family Practitioner - Pediatrician - Psychologist
* Community: Headstart - Community Health Nurse - Better Beginnings - Psychologist (referral
* Childrens' CARE Centre (Health)
* Native Womens' Transition Home
* Community Agencies
* Parents As Teachers
* Legal System
* Community
* AMH
* Detox - AADAC

LIST OF THE ADVANTAGES AND DISADVANTGES OF SUCH A PROTOCOL / PROCESS:

NEGATIVES:

- Risk Of offending the birth mother & loosing client with Headstart Program
- Risk Headstart Program Projecting BAd reputation with Society.
- Labels
- Legal Action - sued
- Control
- Confidentiality

POSITIVES:

- Offer early ontervention
- Understanding of your child's behavior
- Education Of Parents
- Behavior Management Plan
- Funding (eg. HCS) Handicapped Children Services

LIST OF SERVICES - ACTIVITIES - BARRIERS - INVOLVING CHILD IN QUESTION:

I. BIRTH TO SIX MONTHS:

- Family History / Information
- Action Of Doctors
- in family in crises
- distance
- timing
- understanding of values
- extended family support
- child protection services
- hospital
- social services
- Public Health Nurse
    - intrusive
    - Cultural Barriers
- Training very important
- M.D.'s

II. HEADSTART: AGES 3 yrs to 5yrs 11 months:

Teachers Do Assesssment:If able
Program development
Homevisits

- Barriers
- Discrepancies in perception in school & home

- Community Wellness
- Assessment: Denver or DISK:
- Family Physician
- Referral to Pediatrician / Specialists
- Social Services: 3rd party referral to Specialists
- Treatment/ Assessment

III. ECS

IV. SOCIETY:

Transition Home
Outreach
Headstar
Community

DRAFT OF PROCESS

* Admitted to Headstart Program

* Parent Signs Consent

* Teachers Screening: DISK - CONNORS - OTHER TOOLS

* Teacher & Parent —— consent

1. PSYCHOLOGIST
2. PEDIATRICIAN
3. REPORT
4. TEAM CONFERENCE: Planning & Treatment
5. INFORMATION MANAGEMENT
6. Social Service manager / ~~coo~~ coordinator

- Sharing the Dx
- [illegible]
- fit in to cultural milieu
- provide training assistants
- medical treatment +
- Educat^n plan
- "Rehab" referrals
- community support
- funding ?
- transit^n to scho

- EIP
- CARE cent
- Educat^n system
- funding

* use community resources

approval board

- prenatal, nutrit^n, EIP

STRATEGIES:

- Condition Of Admission To Headstart Program
- Informed Consent
- Release Of Information
- Screening Tools
- Consent
- Discharge Information With Family.
- Coordination Of Activities Of Team